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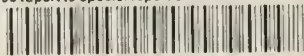
A SPECIAL REPORT ON SERVICES
FOR MONTANA'S CITIZENS WITH
DEVELOPMENTAL DISABILITIES

Montana Developmental Disabilities
Planning and Advisory Council

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A Special Report on Services for Montana's Citizens with Developmental Disabilities

Funded by the
Montana Developmental Disabilities
Planning and Advisory Council

Produced by
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December 1989



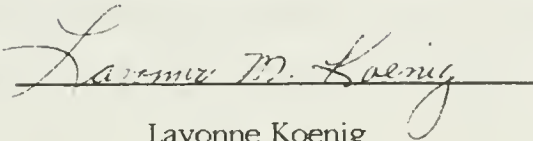
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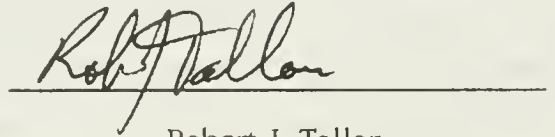
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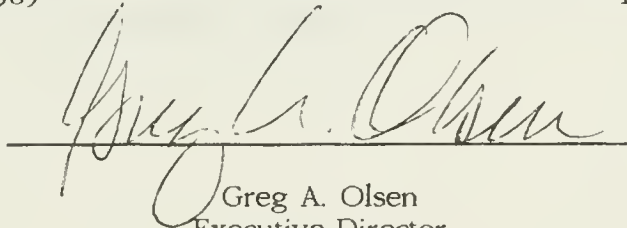
The State of Montana Developmental Disabilities Planning and Advisory Council



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Chairperson
Developmental Disabilities
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1988 - 1989

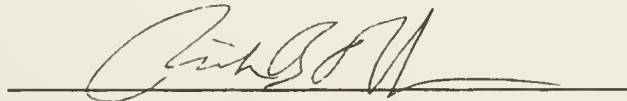


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1990 PLAN RESEARCHED AND WRITTEN THROUGH A CONTRACT WITH:
The Montana University Affiliated Program Satellite



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SUBMITTED, JANUARY 1, 1990, TO:

The Honorable Stan Stephens, Governor of the State of Montana

The State of Montana Legislative Council, Montana Legislature

The United States Department of Health and Human Services, Office of Human
Development Services, Administration on Developmental Disabilities

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INTRODUCTION TO THE 1990 REPORT

WHY THIS REPORT IS BEING PREPARED

Progress in meeting the needs of people with developmental disabilities has been proceeding at a swift pace over the past 30 years, building on new ideas, new power among people with disabilities, and the effects in society of changing public policy.

Change, however, still is needed.

On January 1, 1990, reports will be submitted to the governors and legislatures in every state and territory, chronicling this progress, measuring its impact on people with developmental disabilities and charting the course for continued change and improvement. Congress asked that these reports be done in its 1987 Amendments to the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 100-146). They will be summarized for Congressional review by April 15, 1990.

These reports will assist the state and federal governments in making decisions about public policies; they will also make clear statements about a vision for the lives of people with developmental disabilities in our society. This vision and the values inherent in it will form the backbone of the reports.

A vision expresses beliefs about people with disabilities, about their participation in society and about their rights to the same life, liberty and pursuit of happiness guaranteed to all American citizens. It is the base upon which public policy should be built.

In the Developmental Disabilities Act, Congress has already stated some basic principles and values. Independence, productivity and integration into the community are stated as appropriate goals for people with developmental disabilities and that public policy should assist rather than hinder reaching these goals. These words present a vision not yet fully a reality in the experience of all people with developmental disabilities.

The Councils' reports presented in 1990 will be expressions of a vision that begins with these basic principles set forth in the law and will be expanded and enhanced through

a participatory process defined in the Developmental Disabilities Act. State and territorial Councils are to implement this process in preparing the reports and answering some key questions:

- * Who is getting services funded by public dollars?
- * Who is not receiving services
- * What are those services and what are their goals? Are these goals appropriate and are the services and dollars achieving these goals?
- * What do people with developmental disabilities say about these public policies? How do the services affect them?
- * What new ideas must be incorporated into public policy to better provide the services and supports needed by people with developmental disabilities to achieve the goals of independence, productivity and integration into the community?

STATEMENT OF CONGRESSIONALLY MANDATED PROCESS

Two main activities were required in preparation of the reports. One was a survey of people with developmental disabilities themselves, and their families, to discover what their experiences were and to find out what impact services had in their lives. This consumer survey has become a linchpin in the 1990 Reports' exploration of the policies and practices of American society.

The second was a thorough analysis of existing state and federal public policy and programs to answer the questions of who received services, what kinds of services were available, and what effects those services had.

The Amendments are very clear that attention must be made to all policies and programs, including so-called generic programs which serve people without disabilities. Part of the change in thinking over the past decades has been to realize that segregated services mean segregated lives. While specialized services and programs may still be necessary, all public programs should be responsive to the needs of people with disabilities.

All of this information must be distilled through the Developmental Disabilities Councils, which then make recommendations on how better to meet the needs of all people with developmental disabilities and to promote their independence, productivity and integration into the community. These recommendations were presented to the public for their comment prior to being submitted to the governors and legislatures.

The Councils also have a responsibility to follow through on these recommendations, to advocate for ways to improve our public policy response to people with developmental disabilities, using the authority and resources given to them in federal law.

ROLE OF COUNCIL AS ADVOCATE EDUCATING POLICY MAKERS

The Developmental Disabilities Councils are required by federal law to represent people with disabilities and their families, state agencies, service providers and other persons interested in developmental disabilities. The members are appointed by Governors, giving the Councils stature at the state level to fulfill their responsibilities.

The responsibility of the Councils to develop the 1990 Reports builds upon the role Councils have been filling over their eighteen years of existence. First built into federal law in 1971, Developmental Disabilities Councils have seen their place in state government grow; they are advocates with responsibility to promote better response to the needs of people with developmental disabilities. Funds are provided to the states and territories which the Councils use to respond to the needs of people with developmental disabilities by trying new ideas, exploring and researching public policy questions, and influencing the service system. In the 1987 Amendments, these responsibilities were clearly defined to include education of policy makers, to provide critical information and ideas to improve public programs, and to be in the vanguard for change.

The 1990 Reports present the culmination of many months of effort on the part of Developmental Disabilities Councils but they are more the beginning than an end, for they declare goals and purposes are placed on the public agenda for action. The reports point the way.

OVERALL VISION

The 1990 Reports are an opportunity to influence the specifics of public programs and policies and, as importantly, are an opportunity to express basic principles and beliefs about people with disabilities. Public policy can then be developed which supports and helps fulfill that vision.

The Developmental Disabilities Assistance and Bill of Rights Act provides both a base on which to build and an expression of the pinnacle to which public policy can aspire. It states that:

all persons with developmental disabilities (should) receive the services and other assistance and opportunities necessary to enable such persons to achieve their maximum potential through increased independence, productivity, and integration into the community.

this points to several challenges. It recognizes that services are not the only ways to meet the needs of people with developmental disabilities. Supports of other kinds, such as the supports that come from friends, families, and communities, are critical to people with developmental disabilities. Public policy has too often made the needs of people with developmental disabilities appear to be so specialized that they become deprived of the natural responses and supports that people without disabilities depend upon.

It recognizes that "opportunities" which allow for taking chances, for learning for succeeding and failing are vital parts of life. Public policy must enable these opportunities by eliminating barriers that falsely limit the potential of people with developmental disabilities.

And it states goals for public policy that despite their simplicity have been foiled by many practices supported by public resources:

- * independence: defined as the ability to make choices and to exercise control over one's life;
- * productivity: defined as the opportunity to work and make a contribution;
- * integration into the community: defined as the participation in the richness of life within society not apart from it.

Services that have come out of the traditional mold have not always held to these principles. Services have curtailed decision-making in areas as fundamental as where a person lives and the kind of medical care one gets and as personal as what a person wears. In a free society, the ability to make choices should be curtailed for only the most critical reasons; every effort should be made to support and enable choice. This includes choice over the types of services, supports and other assistance a person with a disability receives.

Being a contributing member of society has too often been thought impossible for people with developmental disabilities. New ideas and approaches are challenging that assumption every day, finding ways to make it possible for people with developmental disabilities to explore their full potential to work, to learn and to make a difference.

The most limiting practice in traditional services has been to separate people with developmental disabilities from the rest of society. Being defined as different required being hidden; having specialized needs required, in effect, meeting those needs behind closed doors, beyond which friends, family and the rest of the community were not allowed. Many view this as the most debilitating practice for it allowed society to forget that people with developmental disabilities existed as part of society, making it easier to deprive and deny them.

Public policy and the programs it supports have put these negative practices into action, affecting thousands of lives. Public policy that allows for not decision making on the part of the person affected, that provides only one type of service that should meet all people's needs, and that continues to brand people with developmental disabilities as less than full citizens has solidified society's worst prejudices.

Again the Developmental Disabilities Act can be referenced as an expression of the values and intentions upon which public policy should be based.

it is in the national interest to offer persons with developmental disabilities the opportunity, to the maximum extent feasible, to make decisions for themselves and to live in typical homes and communities where they can exercise their full rights and responsibilities as citizens. [Sec. 101(a) (8)]

The 1990 Reports' key role is to show how public policy can change so that the vision of full citizenship, including independence, productivity and integration, is understood and made real in the lives of people with developmental disabilities.

Public policy in the current most progressive cases and, if advocacy is successful, in all cases in the future, enables fulfillment of independence, productivity and integration into the community rather than hinder these basic rights.

Independence: people will have choices about which services they want, need and receive; people will be provided supports to exercise their rights and responsibilities rather than have their rights abrogated and their responsibilities diminished; people will control their own destinies rather than have service providers or the limits of our knowledge set false, unnecessary barriers.

Productivity: people will be given the opportunity to learn all they can without prejudgments about their capabilities; people will be given the opportunity to earn a decent living; people will be provided the assistance they need to contribute to society, to help others and to achieve personal goals.

Integration into the community: people will live within society not in separate places cut off from friends, family and regular social contact; people will receive the supports they need and want to enable them to make contact with others and participate in both the grand and the mundane experiences of life in American society.

The hallmarks of this public policy are simple and can be seen affecting the person throughout the life span:

Children should be raised with families in homes to provide affection and love; families should be given the services and supports they need to care for children.

Children should be educated with other children in regular schools and classrooms with supports provided to meet their special needs, enabling them to learn what they need to function in society to their fullest potential.

Adults should live in society and be given the assistance and support they need to lead full, productive lives.

Adults should be able to work and contribute to their fullest potential as all other citizens do.

All people and their families should be allowed to choose what they need to function and not merely receive what services are available, whether or not that will help them to lead fuller lives.

Public policy can and must change to meet these challenges.

CONSUMER INVOLVEMENT IN THE SYSTEM

The advances of the past have come about in large measure through the inspiration and instigation of people with developmental disabilities and their families. They would not be denied their rights to the benefits of society nor would they receive the generosity of society in ways that limited their freedoms and potential. Parents fought to achieve schooling for their children. People with disabilities are fighting for rights to public transportation. People with disabilities are forming support groups to share their views and to work together to make change.

This participation in the political process has also affected how services and supports are provided. More and more the consumer of services is a participant in decision-making rather than being a dependent of the judgments of professionals or managers. Control by the person and family is a key hallmark of progressive services and is evidence in some public policies. The process for developing the 1990 Reports reflect consumer participation. The important role of the consumer survey data in the development of recommendations and the requirement of public review of recommendations validates the opinions and views of people with developmental disabilities.

SERVICES AND SUPPORTS IN A CHANGING ENVIRONMENT

The Developmental Disabilities Assistance and Bill of Rights Act also recognizes that services must be complemented with supports and other assistance. People with developmental disabilities have specialized needs but first and foremost they have aspirations and, as the Act also says, capabilities, competencies and the need for access to the community and its resources. Segregated, specialized services no longer meet all individuals' needs and preferences.

Society's view is changing, partly because people with developmental disabilities can be met in neighborhoods, in schools, in churches and in work places. It has become clear that services and supports can be provided to meet individual needs in order to promote individual accomplishment and a good quality of life. Public policy--and the services it supports--has been moving toward enabling choices, toward supporting productive participation and toward keeping people with developmental disabilities with families and friends. And existing community resources and services are becoming more receptive to people with developmental disabilities, providing services to them as they would to any other individual.

Examples of this changing view can be seen in all sectors. Most dramatic, perhaps, is that fewer and fewer people reside in large, segregated institutions. People with even the most challenging needs are being supported at home with their families or in their own homes. Children with disabilities are being educated with all other children, so that they develop friends, learning from and teaching each other. Children with developmental disabilities are in day care centers and recreational programs alongside their brothers and sisters. Public transportation is becoming more and more accessible, as barriers of technology and attitude are overcome. Providing direct financial support to families to enable them to get the services they decide are needed is one of the fastest-growing types of new service. People with developmental disabilities get jobs every day, not just in sheltered facilities but in work places in the community. And they are being paid real

wages for their work. Health and dental care are available from the community's providers, rather than under the roof of a large institutional facility.

Yet there are still outmoded biases in public policy and implementation which continue to limit the horizons of people with developmental disabilities. The function of the 1990 Reports is to open up those horizons, to aspire to further reaches of possibility for people with developmental disabilities and to propose public policy goals which can accomplish this with the full participation of people with developmental disabilities and their families. This movement can also support change in the views and attitudes of society at large.

LESSONS OF HISTORY

Landmarks of legislative and executive branches' attention to the needs of people with severe disabilities trace the evolution of public policy. Although substantial barriers to independence, productivity and integration into the community still exist in federal and state policy, some recent small yet important new initiatives are changing the direction to more closely coincide with current best practice.

- 1935: Social Security Act includes a requirement that Child Welfare Services become the responsibility of state public child welfare programs with federal support.
- 1946: The National Mental Health Act establishes the National Institute of Mental Health (NIMH).
- 1950: Title XIV of the Social Security Act establishes a federal categorical public assistance program for persons with disabilities, the Aid to Disabled Program.
- 1958: Funds are authorized under the Hill-Burton Act for construction of medical facilities are first used for mental retardation facility construction; rehabilitation facilities are also constructed under the Act.

- 1961: President Kennedy calls together the President's Panel on Mental Retardation.
- 1963: Passage of Mental Retardation Facilities and Community Mental Health Centers Construction Act (Public Law 88-164).
- 1963: The Maternal and Child Health and Mental Retardation Planning Amendments passes (Public Law 88-156).
- 1965: Social Security Amendments (Public Law 89-97) establish Medicaid-Medicare, which pays for health services for the poor, aged and disabled.
- 1965: Title XIX of the Social Security Act authorizes assistance to states to provide medical aid to certain groups. This is the Medicaid program which provides coverage of health care services; later is expanded to cover institutional services.
- 1966: President Johnson creates President's Committee on Mental Retardation as a continuing body.
- 1970: Developmental Disabilities Services and Facilities Construction Act (Public Law 91-517) passes which expands P.L. 88-164 to include other disabilities. Councils are created by this law.
- 1971: The Intermediate Care Facilities Programs is authorized to include institutional services for people with mental retardation. This allows public institutions to get federal support if the institutions meet certain requirements for health and safety and provided what was called "active treatment." This now constitutes the bulk of federal support for services and drives many state systems to continue use of institutional settings.
- 1972: Supplemental Security Income Program (replacing the Aid to Disabled Program) provides a national minimum income for persons who are elderly, blind or have a disability.

- 1973: Rehabilitation Act of 1973 passes, which significantly expands rehabilitation service programs; it includes Section 504 which establishes broad civil rights protections under federal programs for people with disabilities.
- 1975: Education for All Handicapped Children Act (Public law 94-142) passes which enhances the rights of children with disabilities to an appropriate education and provides funds to states to provide educational services.
- 1975: Title XX of the Social Security Act supports services which promote self-sufficiency and avoidance of use of institutional services. Change in 1981 to the Social Services Block Grant and subsequent limits in funding have limited impact even though purposes are supportive of independence, productivity and integration into the community.
- 1975: Developmental Disabilities Assistance and Bill of Rights Act expands P.L. 88-164. Protection and Advocacy is established as a required state program. A "Rights of the Developmentally Disabled" section is added.
- 1978: Amendments to the Developmental Disabilities Assistance and Bill of Rights Act change the definition of developmental disabilities to a set of functional criteria and expanded consumer participation.
- 1978: Centers for Independent Living Program, established under the Rehabilitation Act, creates federal support for community-based, consumer-responsive centers to meet individual needs. Limited funding restricts impact although purposes represent progressive ideas.
- 1981: The Home and Community-Based Waiver Program under Medicaid allows states to apply to get reimbursement of non-institutional services. Although limited in scope and fraught with administrative difficulties for states, this marks a turning point in allowing Medicaid reimbursement for a wide-range of services outside of institutions for certain individuals.
- 1984: The Developmental Disabilities Act is renewed with increased focus on "independence, productivity and integration."

- 1986: Education for All Handicapped Children Amendments (Public Law 99-457) included expansion of federal support to allow services for children in the pre-school ages. It also establishes a discretionary program for early intervention services for children from birth to age 3. Other amendments promote use of technology to meet individual needs.
- 1986: Public Law 99-660 established Comprehensive Planning for Seriously Mentally Ill Individuals to assist states in planning for community-based services to meet the needs of persons with chronic mental illness.
- 1986: The Omnibus Budget Reconciliation Act requires states to prevent and reduce inappropriate placement of persons with mental retardation or mental illness in nursing homes. The required planning and screening process has focused states' attention on the needs of these individuals for a broader range of services in less restrictive, community-based settings. Numbers of persons found to be inappropriately placed indicates attention to this problem was warranted and overdue.
- 1986: Temporary Child Care for Handicapped Children and Crisis Nurseries Act of 1986 (Public Law 99-401) authorizes demonstration grants to provide in-home or out of home care for children with disabilities. This limited program nonetheless does establish federal support for respite care for families with children with disabilities.
- 1987: Supported Employment for Individuals with Severe Handicaps Program funded under the Rehabilitation Act for this innovative employment model which promotes integrated, productive work.
- 1987: Developmental Disabilities Assistance and Bill of Rights Act amended to require Councils to prepare the 1990 Reports and solidifies their role as advocates for public policy change.

- 1987: Civil Rights Restoration Act of 1987 passes to make clear that the Congressional intent of Section 504 of the Rehabilitation Act was to cover institutions receiving federal assistance, not merely programs. This "overturned" the Grove City Supreme Court decision.
- 1988: Fair Housing Amendments Act of 1988 provided protections against discrimination on the basis of disability. A major civil rights act, this establishes firm federal support for full integration into the community.

This history reflects changes in the public policy as expressed by the Congress and implemented by the federal and state governments. It shows a fluidity that can be responsive to new values, ideas and beliefs. The trend is clearly toward more consumer and family involvement and control ("independence"), and community-based, less restrictive supports ("integration").

Tomorrow's history is being written in the recommendations in the 1990 Reports.

THE STATE CONTEXT - SERVICES WITHIN MONTANA

A belief in human dignity, that each person is unique and capable of development, is the cornerstone for the Montana Developmental Disabilities Program. Developmental disabilities such as mental retardation, cerebral palsy, epilepsy and autism place obstacles in the way of individual development.

Over the past fifteen years, both society's view of disabled people and the help offered to handicapped individuals and their families have changed. Community programs have been developed to provide alternatives to placement in state institutions. Montana's statutes document these changes and show a long history of concern for, and commitment to, people with disabilities.

Montana's thrust for providing services to persons with developmental disabilities calls for more normal and less institutional program settings, integration with non-handicapped people, and individual participation in decisions concerning their lives. These changes are a result of many events, including the growing concern for individual rights,

the effectiveness of advocacy groups, and the successes of people with developmental disabilities in community programs.

HISTORIC CONTEXT FOR MONTANA SERVICES: 1970-1990

1970: On January 1, 1970 the population at Montana Developmental Center stood at 865 persons with Developmental Disabilities. At that time the newly appointed Superintendent established deinstitutionalization as the institution's primary method of reform. Shortly thereafter, a nine year plan of resident placement was developed, with the goal for 1979 of a reduction of 665 individuals to a target population of 200. While this goal was not completely met (see Figure 1 in Appendix A), the 1970's saw marked changes in the way services were provided to Montanans with disabilities.

1973- This three year period was and is of major significance in the formation of what is now commonly referred to as the "DD system". From 1973 to 1975, eighteen pieces of legislation relating to developmentally disabled persons were originally enacted and/or amended. Legislation during this period established:

- * Mandates for special education programs for nine categories of school aged handicapped children.
- * Mandates for the Montana School for the Deaf and Blind.
- * Mandates for vocational rehabilitation services for persons with disabilities.
- * Authorized and defined Montana community-based Developmental Disabilities Division Program services.
- * Established protective services for developmentally disabled persons.

1977 Biennium

During this biennium, community-based services were developed across the state which included both residential and day programs. At the conclusion of the biennium, the

number of individuals served in community-based settings increased from 225 to 1,289; 280 of whom left the institution.

1979 Biennium

The number of individuals served in community-based settings increased from 1,289 to approximately 1,550. This was almost entirely due to the development of Child and Family Services. Without an appropriation for expansion of community-based services, waiting lists started to develop, particularly for adult services because of an increasing number of individuals graduating from special education programs.

1981 Biennium

In 1979, the Legislature appropriated \$815,000 for continued deinstitutionalization. During the biennium an additional 62 institutionalized individuals received services in the community. However, during this period few individuals from the community entered services due to lack of appropriate funding. As a result, the waiting lists continued to grow.

1983 Biennium

In 1981, the Legislature appropriated \$1.8 million to address the expanding need to develop additional community-based services for individuals on community waiting lists. During this biennium, approximately 325 individuals from the waiting lists received community-based services.

1985 Biennium

In 1983, the Legislature provided funds to place an additional sixteen individuals from state institutions, as well as money to develop the Title XIX Medicaid Waiver Specialized Family Care program for natural and foster parents to prevent the unnecessary institutionalization of severely handicapped children.

1987 Biennium

In 1985, the Legislature provided \$2.1 million in additional funds, primarily federal Medicaid Home- and Community-Based Waiver spending authority, to serve an additional 278 individuals from the waiting lists.

1989 Biennium

The 1987 Legislature increased the Developmental Disabilities Division's ability to spend federal Medicaid and Education of the Handicapped funds in order to serve persons from the waiting lists. In addition, the state appropriated funds to provide increased individual job placement services to graduates of special education. A total of 195 additional individuals are projected to be served by the end of the biennium. Of the \$975,000 in total annual increased spending authority for expanded services added to the DDD budget, \$925,000 is federal funds while the remaining \$50,000 is state general fund.

1991 Biennium

The 1989 Montana State Legislature approved funding for one Specialized Service and Support Organization (SSSO). The SSSO will provide specialized group home and day program services to a total of 52 severely disabled adults. Key features include 7 specially constructed group homes dispersed throughout the community selected as the site for the SSSO, and one day program in the community to provide coordinated specialized services. A portion of the residents will be individuals placed from the State congregate care facilities in the latest effort to decrease the numbers of persons living there. The facility will be operational in 1991.

In November, 1989, plans developed by the Interagency Task Force on Developmental Disabilities, and endorsed by the governor of Montana call for development of 4 additional group homes in the upcoming biennium. Long range goals call for conversion of the largest state institution into a 60 bed unit designed to serve the group

of people with the most extreme medical or behavior problems (see the section on the Developmental Disabilities Division for further details).

MONTANA'S RECOMMENDATIONS

Each set of Montana's recommendations for each chapter was prepared utilizing at minimum the summary of data from interviews with consumers in Montana. This wealth of data was analyzed by Temple University, Philadelphia, Pennsylvania. In reviewing the data summaries for each item on the survey, if fewer than 85% of the respondents indicated that they were satisfied with the service dealt with in the survey question, it was identified as a service or area needing to be addressed. Attempts were made to group responses and issues together to provide the reader with a relative concern regarding a specific issue on a statewide basis.

The second source employed for Montana's recommendations was the information gathered from Public Forums on Services to Persons with Developmental Disabilities. This served to complement the data available from the consumer surveys. Attempts were again made to group responses and issues together combining the information from the surveys with the forum results.

Additional sources for Montana's recommendations were the current state plans developed for each state department, recently conducted research findings, Task Force recommendations for the future of Montana services, etc.

The organization of each "Recommendations" section begins with the NADDC recommendations. Following those, we have included Montana's recommendations. The majority of Montana's recommendations are followed by the Item number which identifies where the recommendation is derived from in the consumer survey. If the recommendation was derived from the forums or other sources, those will be indicated as well.

The Montana recommendations attributed to the consumer surveys and state-wide public forums represent the views of the consumers. Although the recommendations are

not those of the Council, the Council has reviewed these recommendations and in general concurs with the needs expressed. The Council intends to consider each of the recommendations for their merit as State Priorities for Services, supported or encouraged by the Council.

Demographics of Consumers Surveyed

A total of 98 consumers were surveyed utilizing the Temple University interview instrument. The primary group of respondents involved adults with cognitive impairments, specifically mental retardation. Typical of Montana, the primary ethnic origin of the respondents was white (91%), with the next highest group of respondents being American Indian (7%) (see Figures 2, 3, and 4 in Appendix A).

During the month of September 1989, persons interested in services to people with developmental disabilities met in five locations throughout the state of Montana for public forums. They provided input and recommendations regarding the quality of those services for inclusion in the "1990 Report."

It is the hope of the Developmental Disabilities Planning and Advisory Council that the results of the forums will form a part of the basis for a "Plan for the Future" of services in the state. The Council believes that through the recommendations and opinions of the public the state can review current services, the need for expanded and additional services and thereby, working together, develop strategic and long-range planning that will result in increased and more appropriate services for the persons who need them.

Total attendance at all forums was 137. The Council recognizes that the responses of that number of individuals do not represent a statistically significant analysis of the needs of all persons with developmental disabilities in the state of Montana. What the results do represent is a "snapshot" of opinions and recommendations of persons who are interested in these services. This snapshot is valuable in that it does appear to reflect some of the highest priority needs of the system, based on their inclusion into the discussion in more than one geographical region.

APPENDIX A

FIGURES

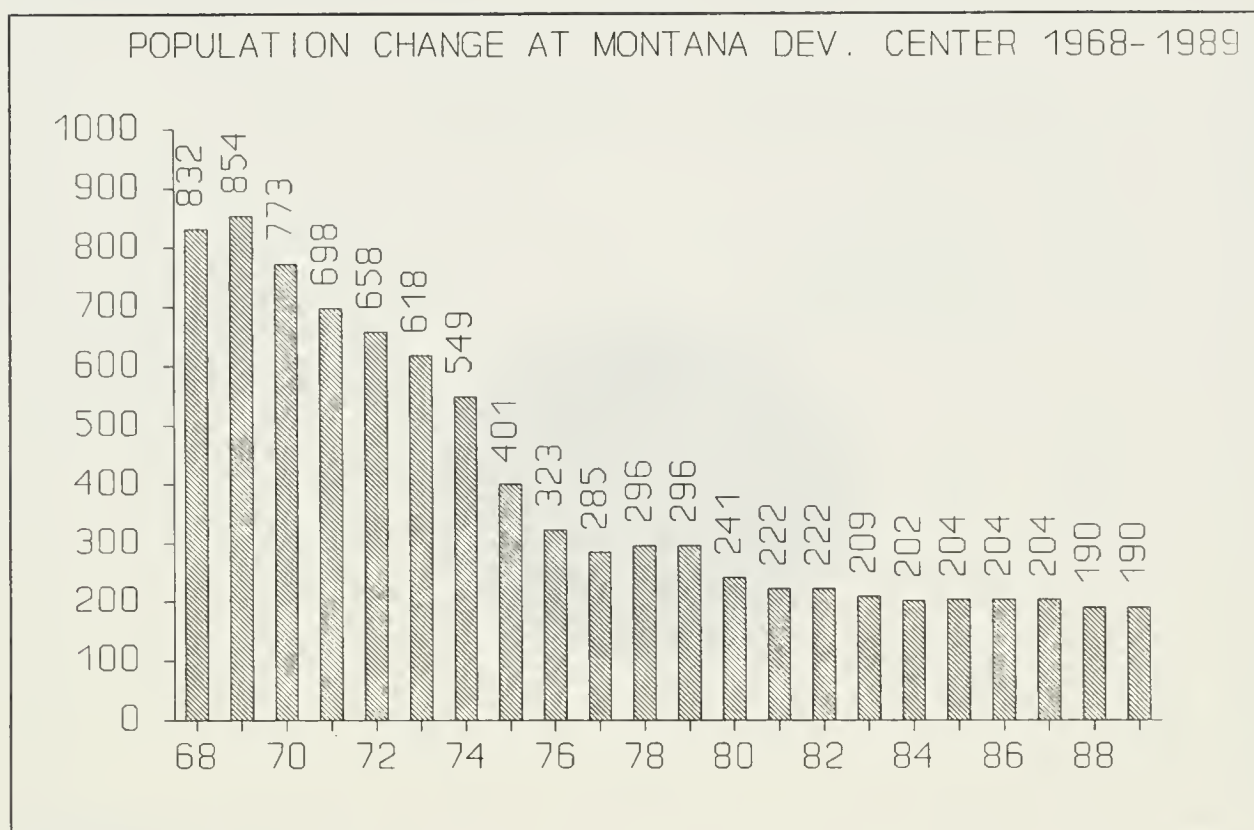


FIGURE 1

DESCRIPTION OF SUBPOPULATIONS

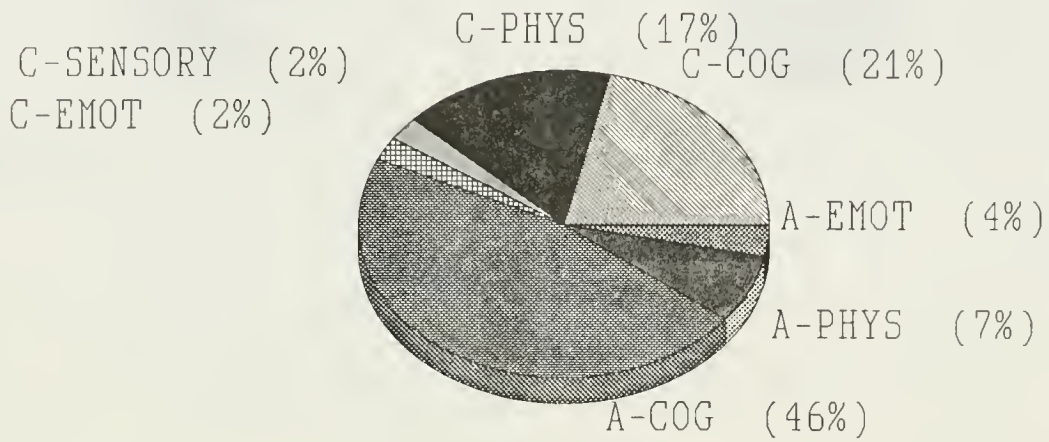
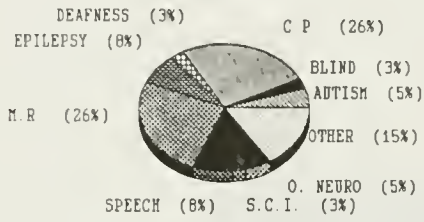


FIGURE 2
Consumer Survey 1989

PRIMARY DISABILITY

CHILD RESPONSE



ADULT RESPONSE

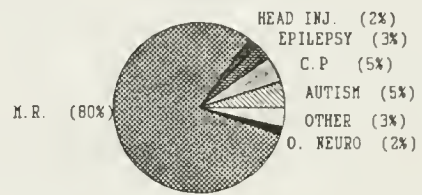


FIGURE 3

Consumer Survey 1989

RACE

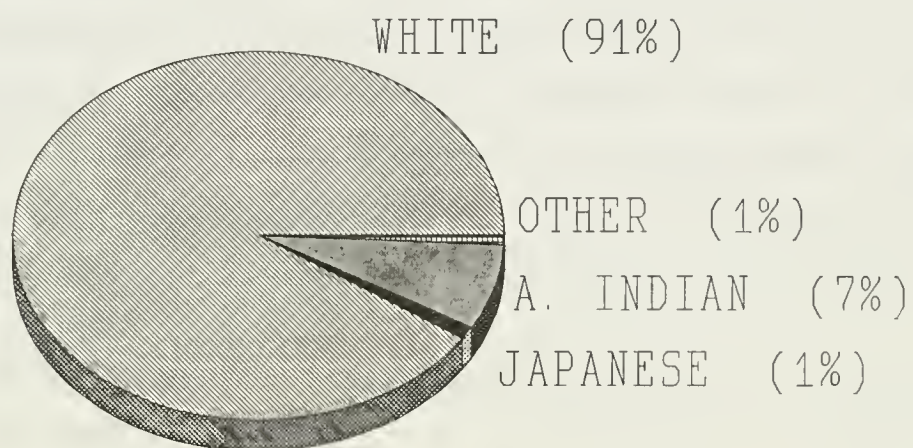


FIGURE 4
Consumer Survey 1989

MONTANA DEVELOPMENTAL DISABILITIES SERVICES CONTEXT

The state of Montana provides a wide variety of services for people with developmental disabilities. More than twenty different categories of state agencies, private non-profit organizations and groups are located throughout the state to either directly deliver services or assist in this process. Provision of services to persons with developmental disabilities is primarily managed by five state agencies as specified by Montana law. The agencies briefly described below and the services that they provide, either through direct service or through contracts, account for the majority of services available in the state.

The Developmental Disabilities Service System is guided by a set of fundamental principles and basic assumptions:

1. All people are capable of learning.
2. Learning is influenced by the characteristics of a person's living and working environment.
3. Individuals exposed to normal and natural patterns of daily life at home, work, and in the community are more likely to develop culturally appropriate, acceptable, and valued behaviors.
4. When appropriate, persons with disabilities should be integrated into, rather than isolated from, the communities in which they reside.
5. Effective services are characterized by a balance of several living, training, and support elements that allow each individual the opportunity to exercise his or her fundamental rights. Training is one aspect of service delivery. Other aspects include a safe, homelike environment; supervision when necessary; recreation and leisure activities; nutritious and good tasting food; clean, appropriate clothing that fits; the dignity of risk; freedom to make choices; community integration, social support, friends, and opportunities for happiness (Interagency Task Force on Developmental Disabilities, 1989).

DEPARTMENT OF FAMILY SERVICES (DFS)

The Department of Family Services was created by the Montana Legislature during the 1987 legislative session and assumed responsibility for services relating to families and youth formerly provided by the Department of Social and Rehabilitation Services (SRS) and the Department of Institutions (D of I).

As it relates to services for persons with developmental disabilities, the DFS provides the following services:

- Case management services
- Child and adult protective services
- Adoption, foster care, and day care programs
- Licensing of adoption, foster care and day care program facilities
- Licensing of group homes for persons with developmental disabilities, utilized by the Developmental Disabilities Division (DDD)
- Information and referral services
- Health-related services as necessary
- Institutional placement and counseling, as needed
- Administration of the State Supplemental Payment program

DFS provided case management services to approximately 1,380 persons with disabilities in the past year. DFS staff license the approximately 80 group homes and 150 to 200 foster homes licensed for developmentally disabled adults and children throughout the state as a small part of their overall licensing responsibilities. The limitations on staff allow them to make only one announced visit per year to each home. Current resources for this function are inadequate, thus providing insufficient time for visits to homes and the lack of possibilities for unannounced visits to assure continued compliance. Follow-up visits do occur when a complaint is filed by DDD field staff, relatives, neighbors, or other concerned individuals.

Through the State Supplemental Payment program, DFS provides a \$94.00 per month state supplement for approximately 500 developmentally disabled in group homes, \$52.25 per month for over 150 children and adults in foster care and \$26.00 per month for 109 adults in transitional living services for the developmentally disabled.

DEPARTMENT OF SOCIAL AND REHABILITATION SERVICES

The Department of Social and Rehabilitation Services (SRS) is one of the state administering agencies responsible for overseeing community-based services for Montana's developmentally disabled population (see Figure 5). The primary agency within SRS administering the community-based array of services is the Developmental Disabilities Division (see Figures 2 and 3).

Developmental Disabilities Division

The Developmental Disabilities Division is the administrative unit within the State Department of Social and Rehabilitation Services primarily responsible for providing community-based services to developmentally disabled individuals (see Figure 6). The Division provides services based on the premise that such services should provide persons with developmental disabilities and their families the training and support necessary to allow the individual to achieve the greatest degree of independence possible. Community services extend into natural living and learning environments in both rural and urban areas.

Services Provided. It is projected that in 1990 the Division will provide or purchase services for 5,642 persons in its community-based programs. It should be noted that the number provides a summation of the count per service available from the Division, and in many cases will represent a duplicated count of individuals receiving more than one service. Figure xx in Appendix C provides data regarding the number of individuals receiving support services from the Division. In Appendix E, Figure xx illustrates the numbers of persons involved in community-based work activities, and Figure xx in Appendix F provides data on the numbers of persons receiving housing assistance from the Division.

The Division's service delivery system makes a wide variety of services available to consumers. Among the available community service options are:

1. Traditional residential services such as adult, children's and senior group homes, or less structured residential options such as transitional and independent living services.
2. Vocational services such as supported employment, work activities and sheltered employment.
3. Non-vocational day services such as senior or intensive day programs.
4. Family support services such as family training, specialized family care, respite care and adaptive equipment.

Definition of Developmental Disabilities. The definition of developmental disabilities used by the Division varies from the federal definition, which at this time is used only by the agencies funded under P.L. 100-146. According to Montana Codes Annotated, Title 53, Chapter 20 Part 202, Montana's definition of developmental disabilities specifies that:

Developmental disabilities means disabilities attributable to mental retardation, cerebral palsy, epilepsy, autism, or any other neurological handicapping condition closely related to mental retardation and requiring treatment similar to that required by mentally retarded individuals if the disability originated before the person attained age 18, has continued or can be expected to continue indefinitely, and constitutes a substantial handicap of the person.

The state of Montana does not specifically follow the federal definition in determining eligibility for developmental disabilities services (see Figure 7). The 1978 changes in the federal law which removed the "disability category" requirement, replacing them with more general statements regarding the extent and severity of the results of the disability, afforded identification of larger numbers of persons with developmental disabilities than Montana's law.

Since the change in the definition contained within federal law, the Montana Developmental Disabilities Planning and Advisory Council (DDPAC) has sought to assist in expanding the scope of services to include persons who have not traditionally been considered eligible for developmental disabilities services in this state. These efforts, in conjunction with those of several state agencies and others, have proven successful in that

several projects have been developed that serve persons who meet the federal definition but are not necessarily persons who would be served under the Montana definition.

The reasons for Montana's continuing utilization of the current statutory definition of developmental disabilities is primarily one of funding. Montana has continually and significantly upgraded and expanded the level and scope of services it provides, as illustrated by increased expenditures for community-based services shown in Table 1. However, even with an approximate 62% increase in the number of persons receiving services in Montana over the last 10 years (1980-1989), the need for expanded services continues to show dramatic growth as well (DDPAC State Plan, 1989).

Waiting Lists. Without considering the impact of revisions of the Montana definition of developmental disabilities, the number of persons waiting for services in the state has risen from 364 in July of 1980 to 1066 in December of 1988. The 1988 figure represents 439 (41%) individuals currently receiving no services and 627 enrolled in developmental disabilities services but identified as in need of more appropriate services. Figure 8 in Appendix B provides detailed information regarding the Division's waiting list.

The growth of the number of persons on waiting lists is partially a function of the maturing of the system, with improved methods of identifying persons in need, and communicating the availability of service to them. More importantly, the rise in the number of persons waiting for services reflects the inability of the system to provide funding for the services needed to address the demand (DDPAC State Plan, 1989).

Montana's Commitment to Prevention of Institutionalization. The Montana service system has for a number of years been resolutely committed to prevention of long-term placement of children or other individuals with disabilities in large congregate facilities. As of December 1988, a total of only 7 children under the age of 19 were residing in institutional settings at the Montana Developmental Center and at Eastmont Human Services Center. This represents only 4.4% of the total population served in the two congregate care

facilities in Montana, and only 10.6% of the total number of children residing in community group homes and institutional settings combined.

In community residential programs, 58 children under the age of 19 are being served by the Division as of September 1989 (see Figure 9). This age group constitutes 6.5% of the total of 903 persons receiving residential services from the Division. The largest group in community residential settings reside in adult group homes (48%). The next largest clusters of individuals receiving Division support for residential placement are the 194 (21%) persons with disabilities in independent or semi-independent living situations and the 109 (12%) persons in transitional living arrangements. Persons with disabilities aged 62 years and older residing in community placements supported by the Division comprise 11% (101) of the total receiving residential services (see Figure 10).

Montana's Developmental Disabilities Division places considerable importance on the value of early detection of disabilities, early intervention services which can prevent future high costs of services for persons with disabilities, and the importance of the family as a focal point for those efforts. Toward those ends, a significant portion (13.5%) of the funding available from the Division is directed into:

1. Evaluation and diagnostic services
2. Family training services to assist parents in working with their children with disabilities
3. Respite services
4. Summer day programs
5. Adaptive equipment
6. Chapter I expenditures to purchase services, equipment, and educational materials

The goal of Division funding for these purposes is to prevent out-of-home placements or institutionalization for children. The Division, DDPAC, and the state's service providers have long recognized that large congregate facilities are not the most desirable living situation for anyone. They have gone to lengths to prevent admissions of individuals, and especially children, to the state institutions for many years. Emphasis

especially for children has been placed upon providing a continuum of services such as family training, case management, respite, and funding for therapies.

This is provided in order that virtually every step has been taken to attempt to ensure that children remain in their own homes with their natural parents or reside in foster homes in a normalized environment.

Carrying the concept of avoidance of out-of-home placement for children as far as possible, in 1983 Montana's state legislature approved the Title XIX Medicaid waiver known as the Specialized Family Care (SFC) waiver. In the first year of operation, 1984, approximately 35 children and families were provided with services. In September, 1989, 101 children (10% of the total children receiving services from the Division) were enrolled in the program, with 5.7% of the Division budget committed for services. In order to be eligible for SFC services, a child must be under 22 years of age and meet the following criteria:

1. The child would be in jeopardy of institutional placement without additional resources.
2. The child has one or more of these characteristics:
 - A. severe/profound mental retardation
 - B. significant maladaptive social and/or interpersonal behavior patterns
 - C. severe medical or health-related problems
3. The child has been determined to be Medicaid-eligible assuming waiver of parents' income eligibility requirements.

In addition to the severity of a child's disability and the degree of stress caused by the care for a child, higher priority is given to children more likely to move to a more restrictive setting.

Through the SFC waiver program, assistance and funding for purchase of services are provided to children and families as follows:

- Case management
- Family training services
- Habilitation aides may be employed
- Respite care
- Transportation assistance

- Minor physical modifications to the home
- OT, PT, speech therapies
- Homemaker services
- Personal care attendant services
- Additional services and equipment
- Foster care

The average annual cost per child receiving this service, \$11,470, is deemed reasonable in relation to the average annual cost per child in a group home of \$20,461, and the cost per year in a congregate care facility of approximately \$54,750. Thus, the motivations for development of SFC waiver services which might have originally had philosophical bases in compassionate ideals of prevention of out-of-home placements of children have realized significant fiscal reinforcement as evidenced in the numbers above.

Expenditure shows trends in by the Division show that in fiscal year 1976 a total budget of \$2,909,885 was available to serve an initial 225 individuals in community settings. Federal sources provided 67% of the funds with the remaining 33% coming from state dollars. Currently, almost 2,400 individuals are receiving community-based services, at a budgeted cost during fiscal year 1989 of \$20,088,957. Federal dollars represent about 70% of the total budget with the remaining 30% coming from the state general fund.

Further Planned Deinstitutionalization. The waiver-funded services have enabled the State to avoid, to some extent, spending substantial amounts of money to bring the institutions into compliance with Medicaid standards, while promoting development of community-based services for formerly institutionalized persons as well as those at risk of institutional placement. However, this avoidance has, as a result, created serious turmoil centered around concerns that active treatment programming in the institutional setting has suffered in this period of growth of community services. This failing is predominantly an effect of the expense in operating two separate residential systems: institutional and community-based. This issue is discussed in more detail in the section of this report addressing Department of Institutions services.

To compensate for these failings, the 1989 Montana State Legislature approved funding for one Specialized Service and Support Organization (SSSO). The SSSO will provide specialized group home and day program services to a total of 52 severely disabled adults. Key features include:

- Seven specially constructed group homes dispersed throughout the community selected as the site for the SSSO
- One single administrative organization to reduce costs and improve service coordination
- A system of specialized professional services (e.g., OT, PT, speech therapy)
- One day program in the community to provide coordinated specialized services
- 70.92% of the cost will be defrayed by federal funding through the Title XIX Medicaid Waiver due to client characteristics and barrier-free residential settings.
- A portion of the residents will be individuals placed from the state congregate care facilities in the latest effort to decrease the numbers of persons living there.

The Division is accepting proposals from communities interested in receiving funding for the SSSO in January 1990. The facility will be operational in 1991.

In November 1989, plans developed by the Interagency Task Force on Developmental Disabilities and endorsed by the governor of Montana call for development of four additional group homes in the upcoming biennium. The long range goals of the Task Force call for development of sufficient community services to enable the state to convert the state institution, the Montana Developmental Center, into a 60-bed unit designed to serve the group of people with the most extreme medical or behavior problems.

Omnibus Budget Reconciliation Act (OBRA). In response to the requirements of the Federal Social Security Act, as amended by the Omnibus Budget Reconciliation Act (OBRA) passed by Congress in 1987, beginning in the Fall 1989, the Economic Assistance Division (EAD) and the Developmental Disabilities Division (DDD) implemented Level I and Level II reviews of clients residing in nursing homes throughout the State. Subparagraph (C) requires that states determine and meet the active treatment needs of

current nursing facility residents, either inside the facility or in newly developed alternative services.

In October 1988, the EAD and DDD identified a total of 306 individuals who appear to have mental retardation or a related condition. Level I and Level II screening processes are expected to be completed by April 1990. EAD directly administers the Medicaid program in Montana and is responsible for ensuring provision of "active treatment services" to those individuals who need such services and choose to continue to remain in nursing facilities. DDD is responsible for developing and administering the alternative community-based services required by those who will no longer reside in nursing facilities.

Following the Level II screenings, EAD and DDD will develop and propose plans to meet the active treatment and other service needs of current nursing facility residents with mental retardation. At the present time it is impossible to identify the specific type and number of services that will be contained in the plans. It is expected that any necessary alternative services will be community-based and include both small ICF/MR and Medicaid Waiver services. Funding will be requested from both the federal and state government in order to provide the services necessary. A request for funding will be submitted by SRS to the governor of Montana for consideration in the executive budget development process, with final consideration and approval coming from the 1991 Montana Legislature. HCFA and HCBS Waiver requests will be developed and submitted for approval to Medicaid funding sources.

Pending approval of state and federal funding mechanisms by approximately June 1993, DDD and EAD activities will be completed, providing active treatment and other service needs for the identified population. Those activities will include development of alternative residences, movement of individuals that choose to reside in those settings, and development of appropriate active treatment services in nursing home settings (Worsdell, 1989).

Gaps in DD Division Services. The following gaps in services provided in the Division's system have been noted:

1. Lack of sufficient community-based intensive residential services. All existing intensive group homes and intensive day services are full. Turnover is rare. Waiting lists are long and growing. People who need intensive services are being placed in the congregate care facilities simply because there are no vacancies in community-based intensive services. Nearly half the clients served in the two congregate care facilities could benefit if intensive services are increased.
2. Sheltered employment programs in Montana have been successful. However, demand for supported employment services exceeds current capacity. Long-term funding for follow-along services is especially in short supply.
3. Limitations exist in the state definition for children eligible for the Part H Education of the Handicapped Act grant intervention program for infants and toddlers aged birth through three years. The definition needs to be broadened and access ensured to a greater array of early intervention services identified as needed.
4. Direct care staff in community-based programs are young, poorly paid, experience a high turnover rate and often lack the skills needed to provide appropriate habilitation services to individuals they serve.
5. Waiting lists for community-based services (e.g., transitional services for young adults graduating high school, Specialized Family Care, respite, adult supported living services) are long and growing. Over 790 Montanans with developmental disabilities need services that are currently not available in sufficient numbers.
6. Lack of appropriate services for persons with developmental disabilities residing in nursing homes.

Vocational Rehabilitation Services

This Division of Social and Rehabilitation Services provides an array of services to individuals with handicaps designed to equalize employment opportunities, to offer other vocational outcomes, and to provide quality of life services for those persons who, because of accident, disease, or congenital deformity, have a physical or mental impairment that constitutes a substantial barrier to optimum normalization.

Eligibility for Vocational Rehabilitation will be determined upon the basis of these established criteria: 1) the presence of a physical or mental disability, which for the individual constitutes or results in a substantial handicap to employment; and 2) a reasonable expectation that Vocational Rehabilitation services may benefit the individual in terms of employability. Vocational Rehabilitation services means any goods and services necessary to render a handicapped individual fit to engage in a gainful occupation.

DEPARTMENT OF INSTITUTIONS (D OF I)

The Department of Institutions is responsible for the operation of the following Montana facilities that provide varying levels of services to persons with developmental disabilities (see Figure 11):

Montana Developmental Center - Boulder, Montana.

The Montana Developmental Center (MDC) is one of the two primary institutional ICF/MR congregate care facilities in the state providing residential services to persons with developmental disabilities.

On July 1, 1970 the population at MDC stood at 865 persons with developmental disabilities. At that time the newly appointed superintendent established deinstitutionalization as the institution's primary method of institutional reform. Shortly thereafter, a nine-year plan of resident placement was developed, with the goal for 1979 of a reduction of 665 individuals to a target population of 200. Figure 1 in Appendix A illustrates the population change at MDC from 1970 to the present. Currently, this facility provides care, treatment, training, education and necessary medical treatment for approximately 185 persons with mental retardation.

As an ICF/MR facility, MDC participates fully in the Medicaid reimbursement program; nearly all of its residents are Medicaid-eligible. From 1977 to the present the ratio of federal to state funding to support the facility has changed significantly. In 1977, state funding represented 75% of the total costs, with Medicaid funds providing the other

25%. By 1988, Medicaid funds constituted 57% of the total cost for maintaining the facility versus 43% provided by the state.

Table 1 provides more detail regarding sources of funding for both institutional and community-based services for Montana's developmentally disabled population. As illustrated in the Table, while the state funding allocations for the congregate care facilities have remained static or even decreased from 1977 to 1988. However, for community-based services, state funding has increased by 231%, and combined state and federal financial support has increased by 346%. In 1987, Montana ranked third in the country in the percentage of developmentally disabled persons receiving residential services in small community-based settings (78%).

Despite progressive deinstitutionalization developments in Montana, in recent years pressures have increased significantly for reorganization of the state's service delivery system for developmentally disabled persons. Currently, the state faces the potential loss of \$7 million in federal Medicaid funds for MDC due to insufficient active treatment services. That factor combined with successful court petitions by six MDC residents for placement in less restrictive, community-based treatment environments has engendered a four-phase reorganization of developmentally disabled services that will create a system consistent with the newly adopted mission to resolve issues that have fragmented past efforts to implement a long-range plan for cooperative integration of all developmental disabilities service providers (Interagency Task Force on Developmental Disabilities, 1989). Toward that end, the 1989 Montana State Legislature approved funding for one Specialized Service and Support Organization (SSSO). This is discussed in more detail in the section on the **Social and Rehabilitation Services, Developmental Disabilities Division**.

As mentioned previously, plans developed by the Interagency Task Force on Developmental Disabilities call for development of four additional group homes in the upcoming biennium. Long-range goals call for converting MDC into at most a 60-bed unit.

Eastmont Human Services Center - Glendive Montana

Eastmont is the other institutional congregate care facility in the state, providing residential services similar to those at MDC. This ICF/MR facility serves a population of approximately 55 persons who are primarily considered to benefit from a smaller, residential-type facility but who are on waiting lists for appropriate community services.

Montana State Hospital - Warm Springs, Montana

The Montana State Hospital is designed to serve persons with a primary diagnosis of mental illness. However, a small population (approximately 25-30 persons) with secondary diagnosis of developmental disabilities typically receive services in the facility.

Center for the Aged - Lewistown, Montana

The Center for the Aged is a 191-bed facility for the long-term care of persons fifty-five or older who have chronic mental disorders associated with the aging process. The Center has a small changing population of persons with a diagnosis of developmental disabilities (approximately 5 - 10).

Community Corrections Facilities and Programs (offenders with developmental disabilities) - Statewide

Persons with developmental disabilities under the jurisdiction of corrections facilities in Montana may have access to the following types of services:

- Mental health services
- Drug and alcohol counseling
- Public assistance
- Vocational rehabilitation services
- Adult basic education services
- Job Services Division, Department of Labor

Mental Health and Residential Services Division - Statewide

This Division administers all funds available for and contracts with the five regional community health centers to provide community mental health services. Additionally, the Division is responsible for the overall planning, budgeting and program monitoring for all state operated residential facilities, but does not provide direct services to these facilities.

DEPARTMENT OF HEALTH AND ENVIRONMENTAL SCIENCES (DHES)

The Department of Health and Environmental Sciences is responsible for provision of services as follows (see Figure 12):

1. Women with low income or limited access to health care are to be assured quality maternal and child health services.
2. Reduction of infant mortality and incidence of preventable disease and handicapping conditions among children.
3. Provision of rehabilitative services to blind and disabled individuals under the age of 16 and who are receiving benefits under Title XVI.

In meeting those responsibilities, the Family/Maternal and Child Health (F/MCH) Bureau of DHES maintains administrative responsibility for the following programs: Handicapped Children's Services; Family Planning; Women, Infants, and Children (WIC); and the Child Nutrition Program - Child Care Food Program. Additionally, the F/MCH Bureau administration includes Maternal and Child Health Aid to Counties, Newborn Metabolic Screening, F/MCH Staff Development, and a Special Project of Regional and National Significance.

Title V amendments enable DHES to provide medical, surgical, or corrective services for crippled children or children who are suffering from conditions leading to crippling. Referral to facilities for diagnosis, hospitalization, and aftercare is also provided. The F/MCH Bureau furnishes medical direction to the Newborn Metabolic Screening Program in which each newborn infant in Montana is tested for phenylketonuria (PKU), galactosemia, and hypothyroidism.

The F/MCH Bureau administration administers a Special Project of Regional and National Significance funded from the MCH block grant. The program, entitled "Children with Special Health Care Needs," is a community-based, multi-discipline program developed to assist Montana children and their families with their special health care needs. The program's primary concentration is case management for children with special health needs in Montana's frontier communities.

The Handicapped Children's Services (HCS) program is concerned with the early detection, diagnosis, rehabilitation, and prevention of physically handicapping conditions in children with special health care needs from birth to age 18. Services are provided to children who meet income guidelines currently set at 185% of the poverty level as annually determined by the federal government. Eligibility for the program is determined by the severity of the handicapping condition, gross family income, family size, and availability of alternative sources of payment.

For those who are eligible, HCS will pay for evaluation and diagnostic services arranged through private provider, regional center, and clinics. In addition, HCS will pay for approved surgery and related hospitalization, special medications and infant formulas, genetic evaluations, braces, and other therapies as needed. The emergency medical transport of newborn infants and their mothers can also be covered.

Family Planning services aid in reducing the incidence of premature births, low birth weight, birth defects, and abortions. Complementary to its role in preventive health planning, Family Planning also offers diagnosis or referral for general health problems that can affect future pregnancy, fetal development, and maternal health.

Family Planning is primarily financed with federal Title X and PHHS and MCH Block Grant funds, therefore requiring periodic evaluation of local agencies to ensure compliance with federal guidelines.

WIC assists low-income pregnant and breast feeding women, women who have recently given birth, and infants and children up to age five who are at health risk. Assistance is in the form of nutrition assessment, education, and counseling to improve

eating behavior; supplemental food with high nutritional value; access to health care programs; and, prenatal and pediatric care referrals.

Infant mortality rates are reduced through decreased incidence of low birth weight babies; and infants and children benefit from a healthy start in life with their nutritional needs being met at this important developmental stage in their lives. The program is funded with a USDA grant, administered by the DHES through State rules (ARM 16.26.101).

The Child Nutrition Program - Child Care Food Program provides reimbursement for meals meeting specific nutritional requirements which are served to children enrolled in licensed, nonprofit, nonresidential licensed or approved child care centers, Head Start programs, child care homes, and outside-school-hours programs. Private, for-profit centers that receive compensation under Title XX of the Social Security Act for at least one-fourth of non-resident children receiving care may also qualify for the Program.

The Montana Perinatal Program, through several activities, is dedicated to the improvement of pregnancy in Montana by promoting reduced mortality, morbidity, and disability during the perinatal period. The Perinatal Program is also involved with prevention of the birth of low birthweight infants through local or community project funding.

DHES assists the public schools in seeking out, evaluating and referring handicapped children, aged 0 through 5. They maintain a record of all handicapped children, age 0 through 5, who are served by state agencies or grantees of state agencies serving as the prime agency responsible for tracking all handicapped children, age 0 through 5. At least annually, DHES reviews all known handicapped children, age 0 through 5, to assure that children are being served or that the individual services plan has been completed.

DHES provide case management of persons suspected of being developmentally disabled until the person is evaluated. If an evaluation indicates that a person is primarily developmentally disabled, SRS then provides case management and develop the individual services plan upon referral from DHES.

OFFICE OF PUBLIC INSTRUCTION/DEPARTMENT OF SPECIAL SERVICES (OPI)

This Montana state agency is responsible for ensuring that all handicapped children in Montana receive a free, appropriate public education provided in the least restrictive alternative setting. To the maximum extent appropriate, handicapped children, including children in public or private institutions or other care facilities, are educated with children who are not handicapped. Separate schooling or other removal of handicapped children from the regular educational environment may occur only when the nature or severity of the handicap is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.

After September 1, 1977, the board of trustees of every school district was required to provide or establish and maintain a special education program for every handicapped person between the ages of 6 and 18, inclusive.

On or before September 1, 1990, the board of trustees of each elementary district must provide or establish and maintain a special education program for each handicapped child between the ages of 3 and 6, inclusive. The board of trustees of any school district may meet its obligation to serve handicapped persons by establishing its own special education program, by establishing a cooperative special education program, or by participating in a regional services program.

Montana State policies assure and include but are not limited to:

- (a) placement of handicapped children in the least restrictive alternative setting;
- (b) due process for all handicapped children, including the appointment of a surrogate parent if necessary;
- (c) use of child study teams to identify handicapped children and use of instructional teams to plan individual education programs;
- (d) comprehensive evaluation for each handicapped child; and
- (e) other policies needed to assure a free and appropriate public education.

Total numbers served, funding sources, and related information are addressed in the chapter on Education (ORI State Plan, 1989).

Deaf/Blind Programs

The Department of Special Services is the entity within the Office of Public Instruction which is responsible for the supervision and coordination of special education within the state; the Title VI-C Severely Multihandicapped Deaf/Blind Program is a part of Special Services.

Deaf/blind children are being served in the public schools throughout Montana in classrooms specifically for deaf/blind and also with the severely multihandicapped. They have the same supportive services, and in several instances a special aide is hired to work with those children. Funding and operation of day-to-day deaf/blind education programs is totally based on federal funds.

MONTANA CENTER FOR HANDICAPPED CHILDREN

The Montana Center for Handicapped Children (MCHC) has been providing comprehensive diagnostic evaluation, special education and related services to handicapped children and their families for the past 39 years. MCHC currently provides comprehensive diagnostic services to approximately 250 children (140 from Yellowstone County) per year as well as providing comprehensive special education and related services to approximately 25 children per year within the school program and providing outpatient and outreach services.

The Montana Center for Handicapped Children also provides a specialized, data-based, individualized special education and related services program for handicapped children ranging from age 0 to 21 years of age. There are presently three classrooms being operated at this Center on a full-day basis.

MENTAL DISABILITIES BOARD OF VISITORS

The Mental Disabilities Board of Visitors serves institutionalized persons with developmental disabilities and persons in the institution and community who are mentally

ill. The services/duties of the Board are legislatively mandated. The services include:

- a. Review of patient care and treatment at the following facilities: Eastmont Human Services Center, Montana State Hospital: Warm Springs and Galen Campuses, Montana Developmental Center, Riverdale Facilities, Montana Center for the Aged, and the five regional mental health centers and their satellites.
- b. Assistance to any patient in resolving any grievance with regard to their commitment and/or treatment.

The Board responded to more than 1500 grievances during fiscal year 1988.

MONTANA SCHOOL FOR DEAF AND BLIND

The Montana School for the Deaf and Blind (MSDB) is open to every visually and hearing impaired child in Montana--from birth through the age of 21. There is no charge for enrollment or for room and board. MSDB offers its students the same academic subjects as public schools, fulfilling the same Board of Public Education requirements. Added emphasis is on language development for the hearing impaired and life skills for the visually impaired.

Summary of Service Populations:

a.	Enrolled at Great Falls Campus	117
	Hearing Impaired	101
	Visually Impaired	16
	Deaf/Blind Multi-handicapped	7
b.	Outreach and Itinerant Services	241
	Parent/Infant	43
	Deaf/Blind Local	7
	Visually Impaired Itinerant	191
c.	Total Serviced By Agency	358

MONTANA ADVOCACY PROGRAM

MAP provides advocacy services to developmentally disabled person who are having difficulty obtaining appropriate services or exercising their rights.

MAP does not solicit clients; initial contact is made by the potential client, a representative, or another concerned party. The first step taken by MAP is to issue a Release of Information form to the client or guardian, authorizing MAP to receive and disseminate information, within the bounds of client confidentiality.

Further information regarding MAP is contained in the **Civil Rights** chapter.

BILLINGS AREA - INDIAN HEALTH SERVICES

Indian Health Services (IHS) are available to all individuals of Indian and/or Alaskan native descent. IHS contract care services are available to those eligible individuals who meet the residence requirements established by Congress.

These services are provided at the various IHS hospitals and health centers located on the seven Montana Reservations. Services include, but are not limited to: medical care, dental services, surgical and para-medical services which may vary as a function of location and staffing.

MONTANA UNIVERSITY AFFILIATED PROGRAM SATELLITE

The Montana University Affiliated Program is part of the national network of programs funded by the federal Administration on Developmental Disabilities (ADD) committed to assisting in the provision of interdisciplinary training, conducting service demonstration programs, and disseminating information that increases and supports the independence, productivity, and integration into the community of persons with developmental disabilities.

MUAP now is a major component--with its sister program the Research and Training Center on Rural Rehabilitation Services (RTC:Rural)--of the University's newly

established Institute for Human Resources (IHR) in Rural America that has 45 faculty and staff, occupying over 10,000 square feet of office and classroom space on the campus.

Over the past ten years of operation, the MUAP has grown in many ways, from numbers of staff and projects to the size of its office space. The acquisition of funds has increased almost twentyfold: from \$126,000 in FY 1979 to nearly \$2,000,000 this year. The MUAP now generates an additional \$12 for every \$1 of core funding received from the Administration on Developmental Disabilities.

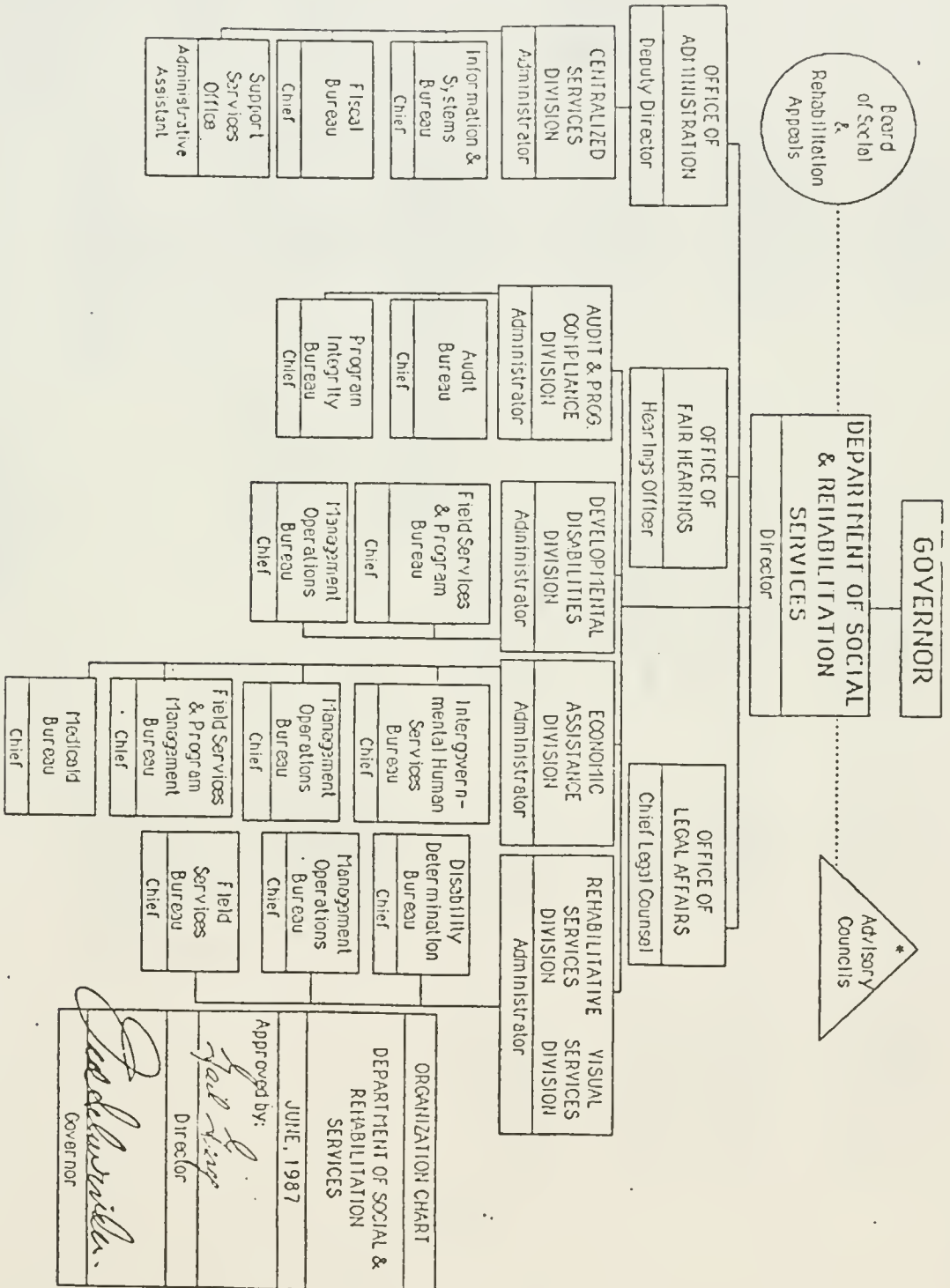
Since its beginning, the MUAP has attracted over \$6.8 million in grants and contracts, not including continuation funding expected on current projects. Importantly, thirty-six percent of these resources has gone directly to state or community-based agencies to support enhancement of the state's service system.

REFERENCES

- Interagency Task Force on Developmental Disabilities. (1989). Action plan for modification of the Montana developmental disabilities. Helena, MT: Interagency Task Force on Developmental Disabilities.
- Office of Public Instruction. (1989). Fiscal years 1990-1992 state plan. Helena, MT: Office of Public Instruction.
- Worsdell, L. (1989). Alternative disposition plan for persons with developmental disabilities. Helena, MT: Developmental Disabilities Division.

APPENDIX B

FIGURES AND TABLES



* Advisory Councils attached to the Department of Social and Rehabilitation Services are listed on page 19.

Developmental Disabilities Division

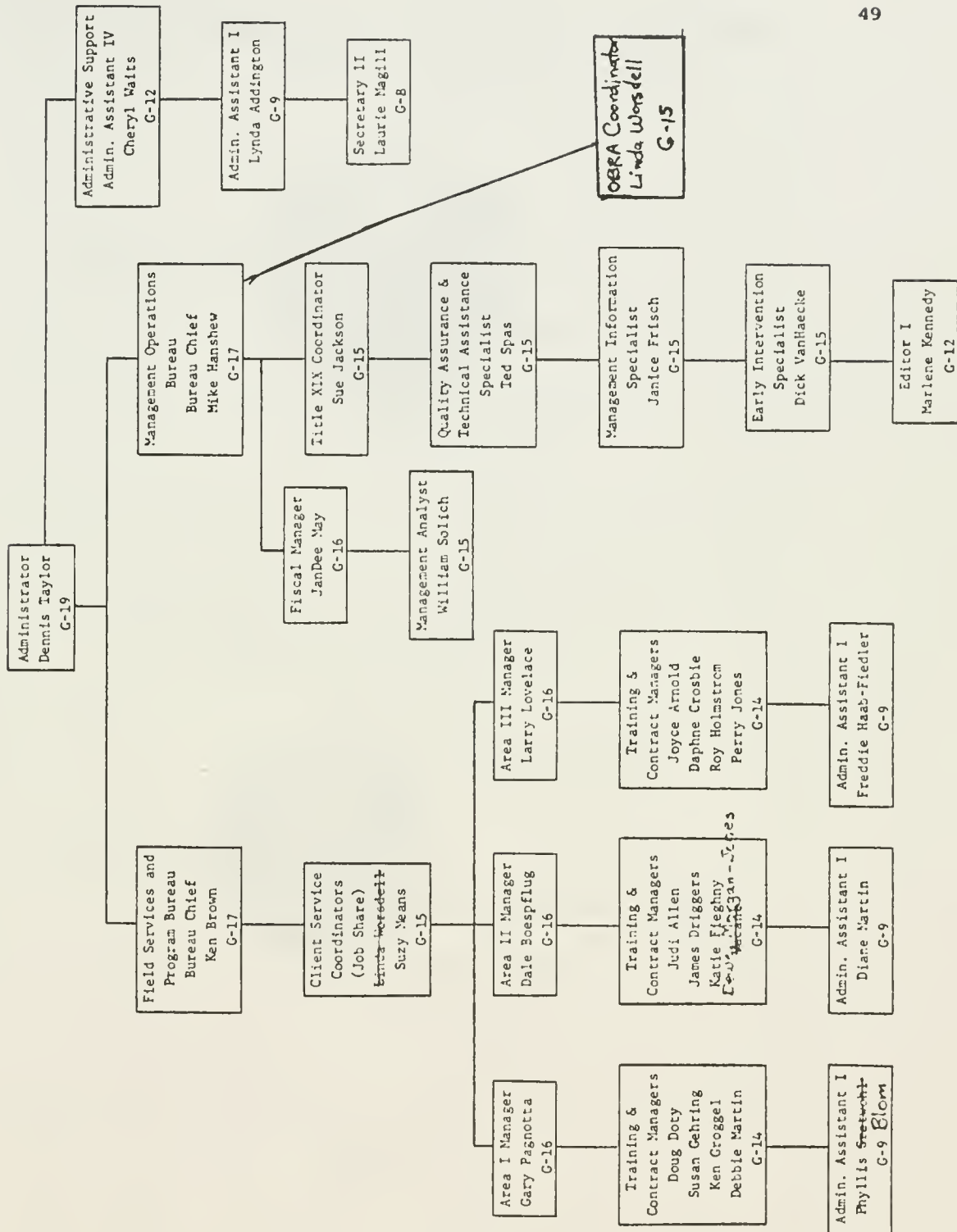


FIGURE 6

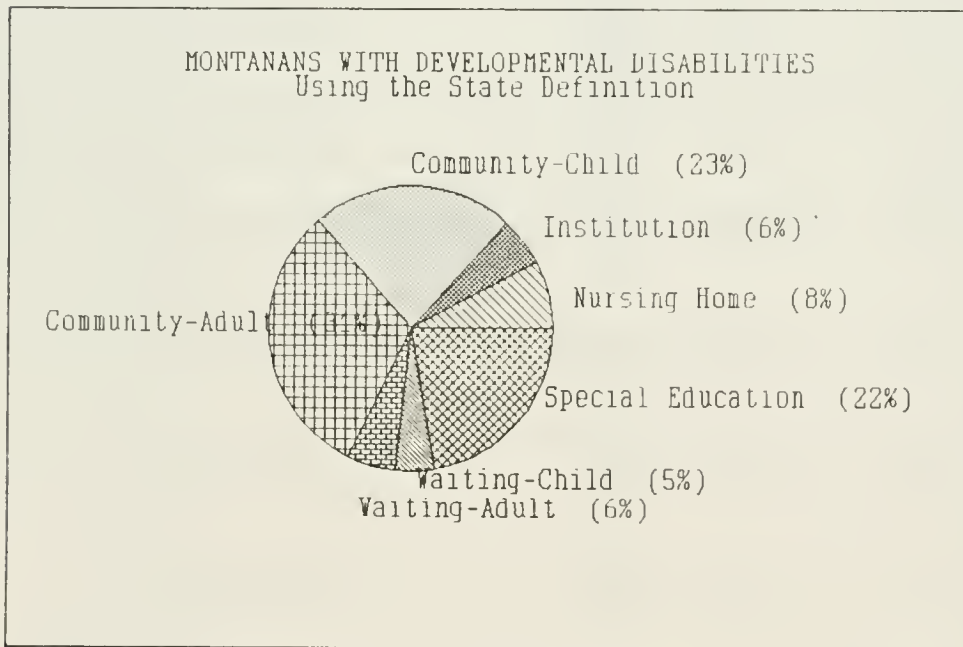
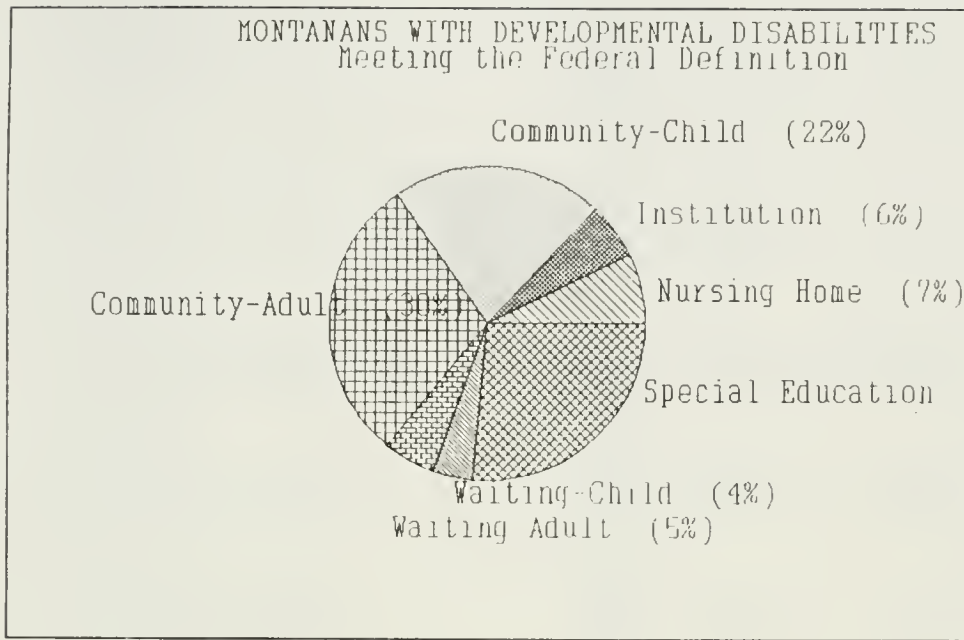


FIGURE 7

MONTANA

Financial Support for MR/DD Services: FY 1977-88

MONTANA 5/3/89	1977	1978	1979	1980	1981	1982	1983	1984	1985	1986	1987	1988
TOTAL FUNDS	\$14,331,000	\$15,871,000	\$16,063,000	\$17,553,000	\$19,563,000	\$22,197,652	\$28,067,772	\$28,548,916	\$27,988,400	\$29,811,288	\$32,091,500	\$33,730,560
CONGREGATE 16+ BEDS	8,606,000	6,740,000	8,628,000	9,652,000	10,165,000	11,680,000	12,911,000	12,395,400	12,682,900	12,830,100	13,405,200	13,883,700
INSTITUTIONAL SERVICES FUNDS												
STATE FUNDS	8,606,000	8,740,000	8,628,000	9,652,000	10,165,000	11,680,000	12,911,000	12,395,400	12,682,900	12,830,100	13,405,200	13,883,700
General Funds	6,534,000	5,716,000	5,772,000	6,255,000	6,036,000	8,160,000	7,988,000	6,151,500	7,029,400	6,122,800	6,407,500	5,965,400
Other State Funds	6,264,000	5,436,000	5,516,000	5,929,000	5,810,000	6,978,000	7,764,000	5,986,600	6,888,600	6,109,300	6,404,300	5,960,400
FEDERAL FUNDS	270,000	260,000	256,000	326,000	226,000	1,182,000	224,000	164,900	140,800	13,500	3,200	5,000
Federal ICF/MR	2,072,000	3,024,000	2,856,000	3,397,000	4,129,000	3,520,000	4,923,000	6,243,900	5,653,500	6,707,300	6,997,700	7,928,300
Title XX / SSBG Funds	2,015,000	2,830,000	2,731,000	3,268,000	4,027,000	3,429,000	4,873,000	6,191,300	5,607,700	6,668,900	6,930,900	7,901,800
Other Federal Funds	57,000	194,000	125,000	129,000	102,000	91,000	50,000	52,600	45,800	38,400	66,800	26,500
LARGE PRIVATE RESIDENTIAL												
STATE FUNDS	0	0	0	0	0	0	0	0	0	0	0	0
General Funds	0	0	0	0	0	0	0	0	0	0	0	0
Other State Funds	0	0	0	0	0	0	0	0	0	0	0	0
FEDERAL FUNDS	0	0	0	0	0	0	0	0	0	0	0	0
Large Private ICF/MR	0	0	0	0	0	0	0	0	0	0	0	0
COMMUNITY SERVICES FUNDS	5,725,000	6,831,000	7,435,000	7,901,000	9,398,000	10,517,652	13,156,772	14,153,516	15,305,500	16,781,168	18,686,300	19,836,880
STATE FUNDS	2,473,000	4,342,000	4,260,000	3,771,000	4,962,000	9,241,000	9,689,000	10,289,600	10,990,000	3,522,600	5,722,900	5,723,600
General Funds	2,284,000	4,128,000	4,051,000	3,554,000	4,737,000	9,006,000	9,423,000	10,044,600	10,731,000	3,249,800	5,174,000	5,226,600
Other State Funds	0	0	0	0	0	0	0	0	0	10,800	12,900	0
SSI State Supplement	189,000	214,000	209,000	217,000	225,000	235,000	266,000	245,000	259,000	262,000	536,000	497,000
FEDERAL FUNDS	3,252,000	2,589,000	3,175,000	4,130,000	4,436,000	1,276,652	3,467,772	3,863,916	4,315,500	13,258,568	12,963,400	14,113,280
ICF/MR Funds	18,000	20,000	23,000	40,000	44,000	20,000	21,000	90,300	86,500	93,200	103,700	108,500
Small Public	0	0	0	0	0	0	0	0	0	0	0	0
Small Private	18,000	20,000	23,000	40,000	44,000	20,000	21,000	90,300	86,500	93,200	103,700	108,500
HCBS Waiver	0	0	0	0	0	244,000	534,000	808,000	980,700	2,268,000	2,415,700	3,024,500
Model 50/200 Waiver	0	0	0	0	0	0	0	0	0	0	0	0
Other Title XIX Programs	0	0	0	0	0	0	0	0	0	0	0	0
Title XX / SSBG Funds	3,234,000	2,381,000	3,083,000	4,019,000	4,234,000	902,000	2,698,000	1,351,800	1,348,800	10,186,000	9,602,200	9,496,200
Other Federal Funds	0	188,000	69,000	71,000	158,000	56,000	87,000	1,398,800	1,629,500	62,000	48,000	376,000
Waiver Clients' SSI/ADC	0	0	0	0	0	54,652	127,772	215,016	270,000	649,368	793,800	1,108,080

COMMUNITY SERVICE WAITING LIST, DECEMBER 1988

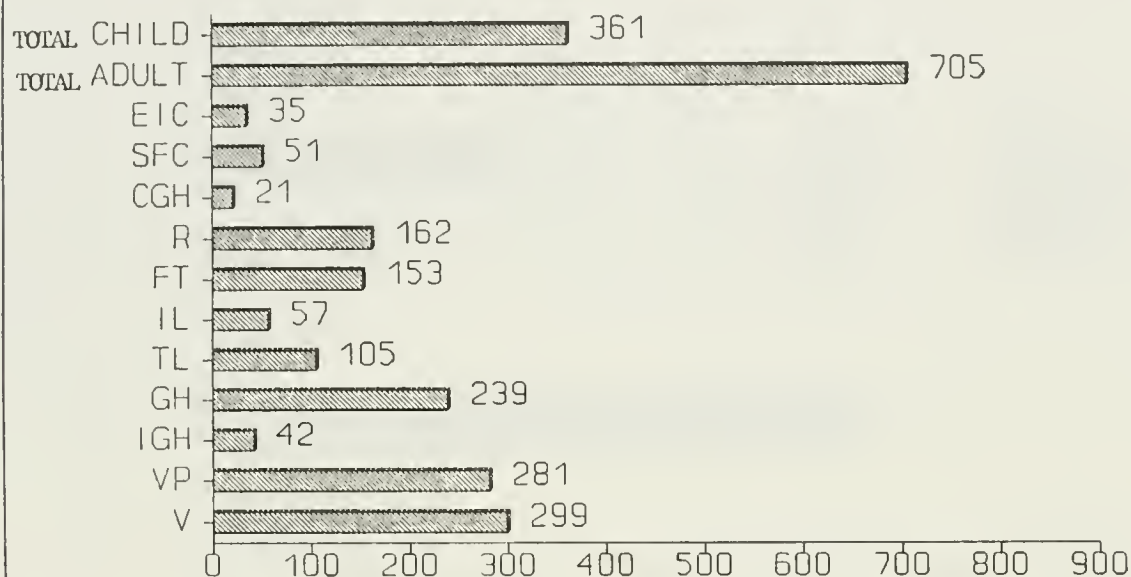


FIGURE 8

V = Vocational/Day Services
VP = Vocational Placement
IGH = Intensive Group Home
GH = Adult Group Home
IL = Transitional Living Service

IL = Independent Living Training
FT = Family Training
R = Respite
CGH = Children's Group Home
SFC = Specialized Foster Care
EIC = Early Childhood Intervention

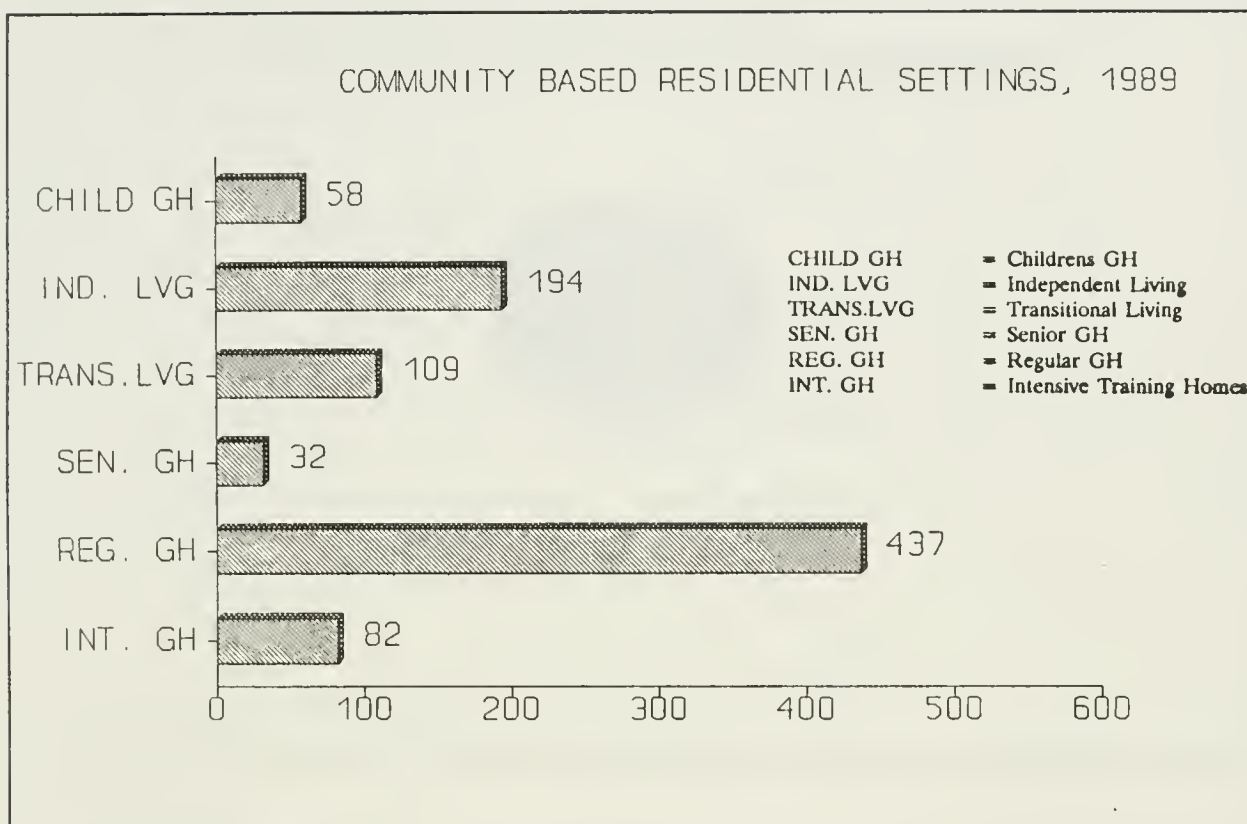
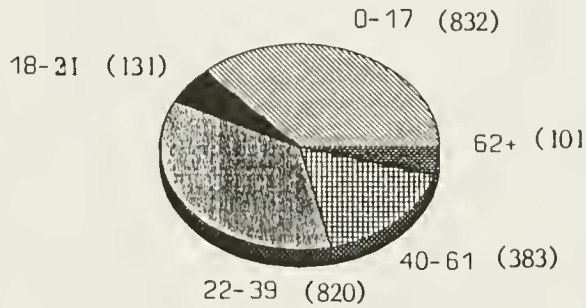


FIGURE 9

AGE DISTRIBUTION FOR MONTANA COMMUNITY BASED SERVICES



MT COMMUNITY BASED SERVICES HANDICAPPING CONDITIONS DISTRIBUTION

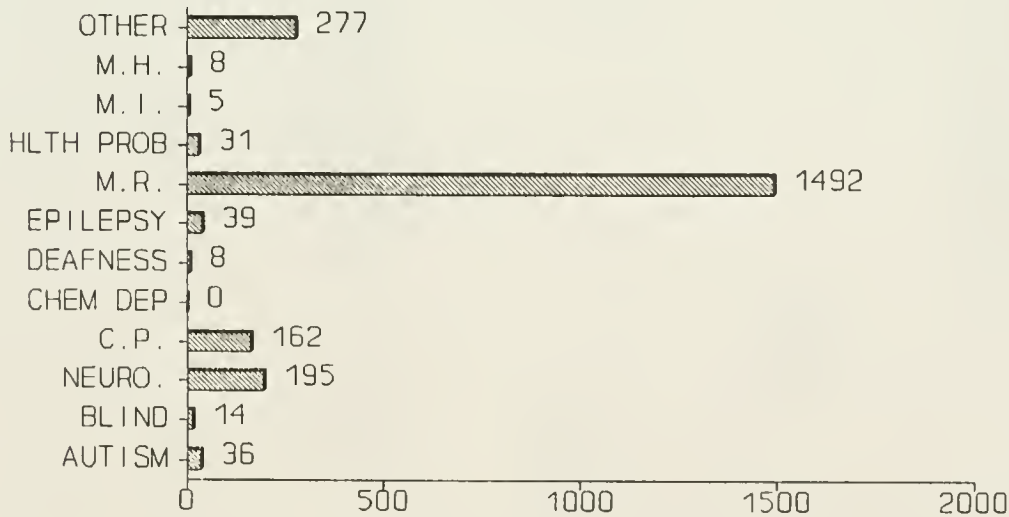


FIGURE 10

BLIND	= Blindness
NEURO	= Brain/Neurological/LD
C.P.	= Cerebral Palsy
CHEM. DEP	= Chemical Dependency
M.R.	= Mental Retardation
HLTH PROB	= Health Problem
M.I.	= Mental Illness
M.II.	= Sit. Mental Health/ED

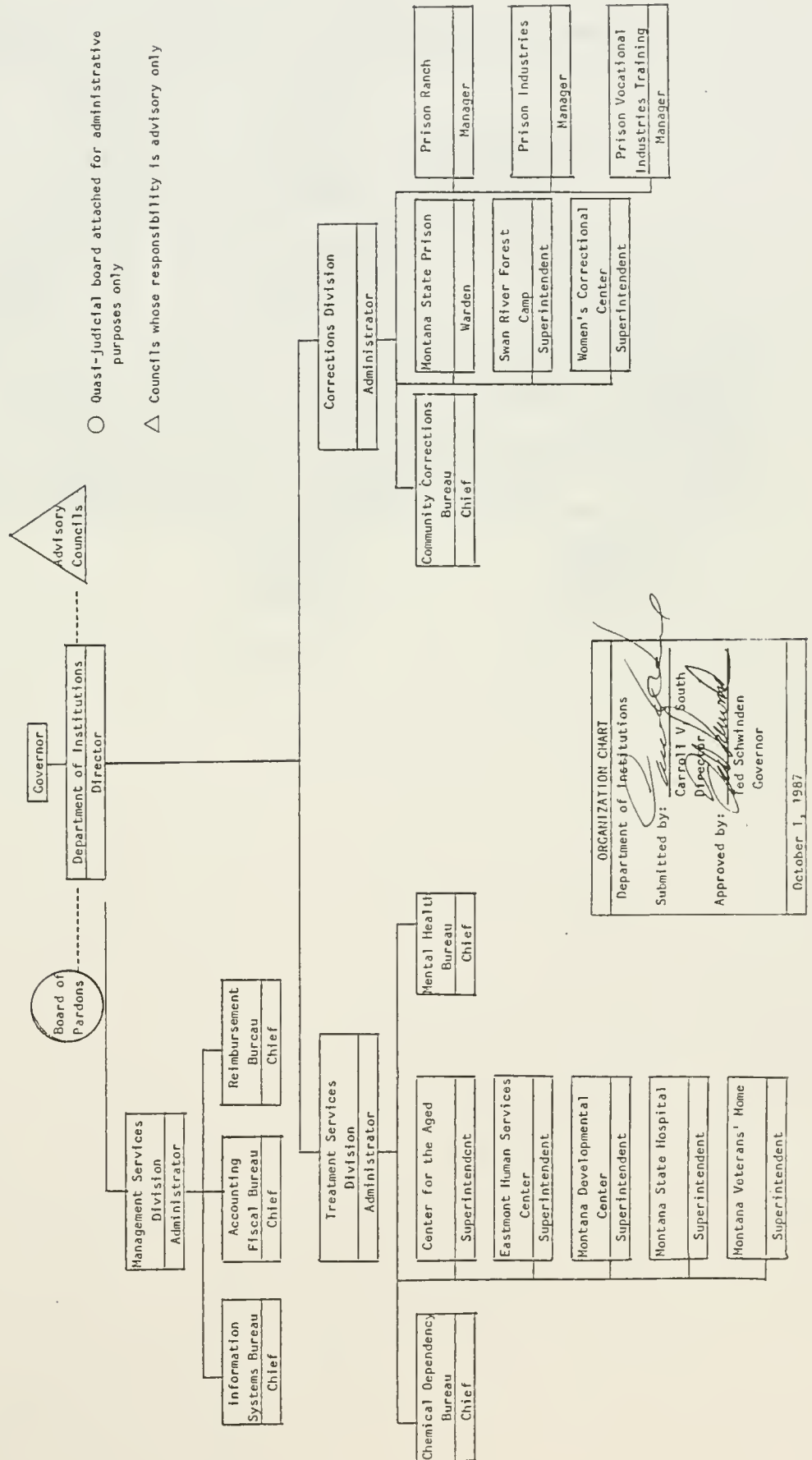


FIGURE 11

ORGANIZATION CHART DEPARTMENT OF HEALTH AND ENVIRONMENTAL SCIENCES

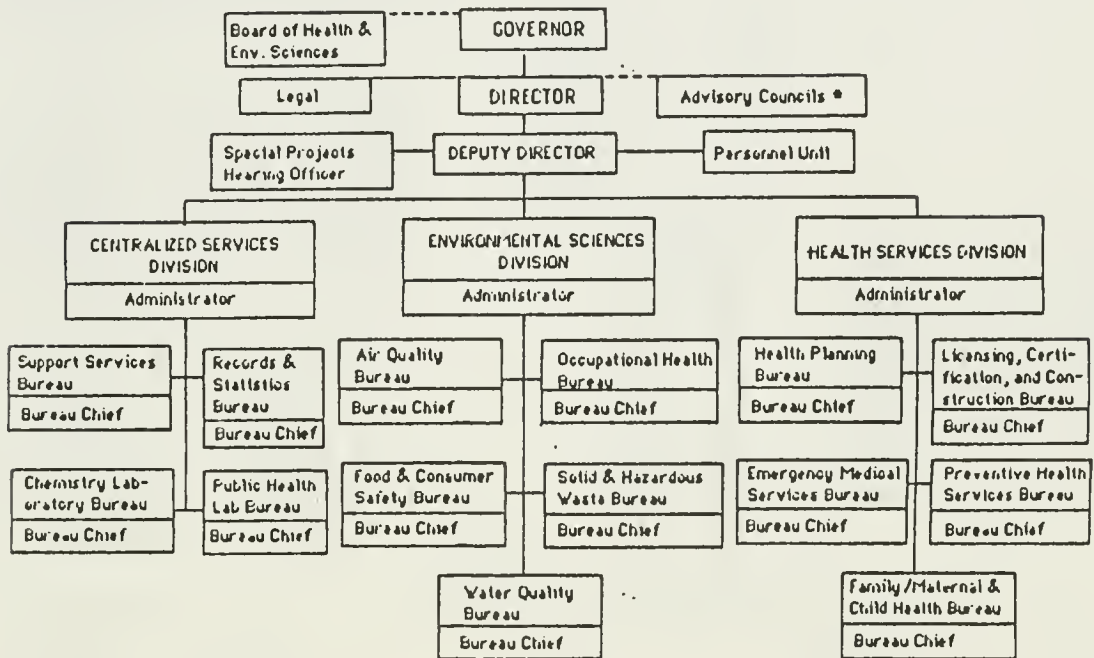
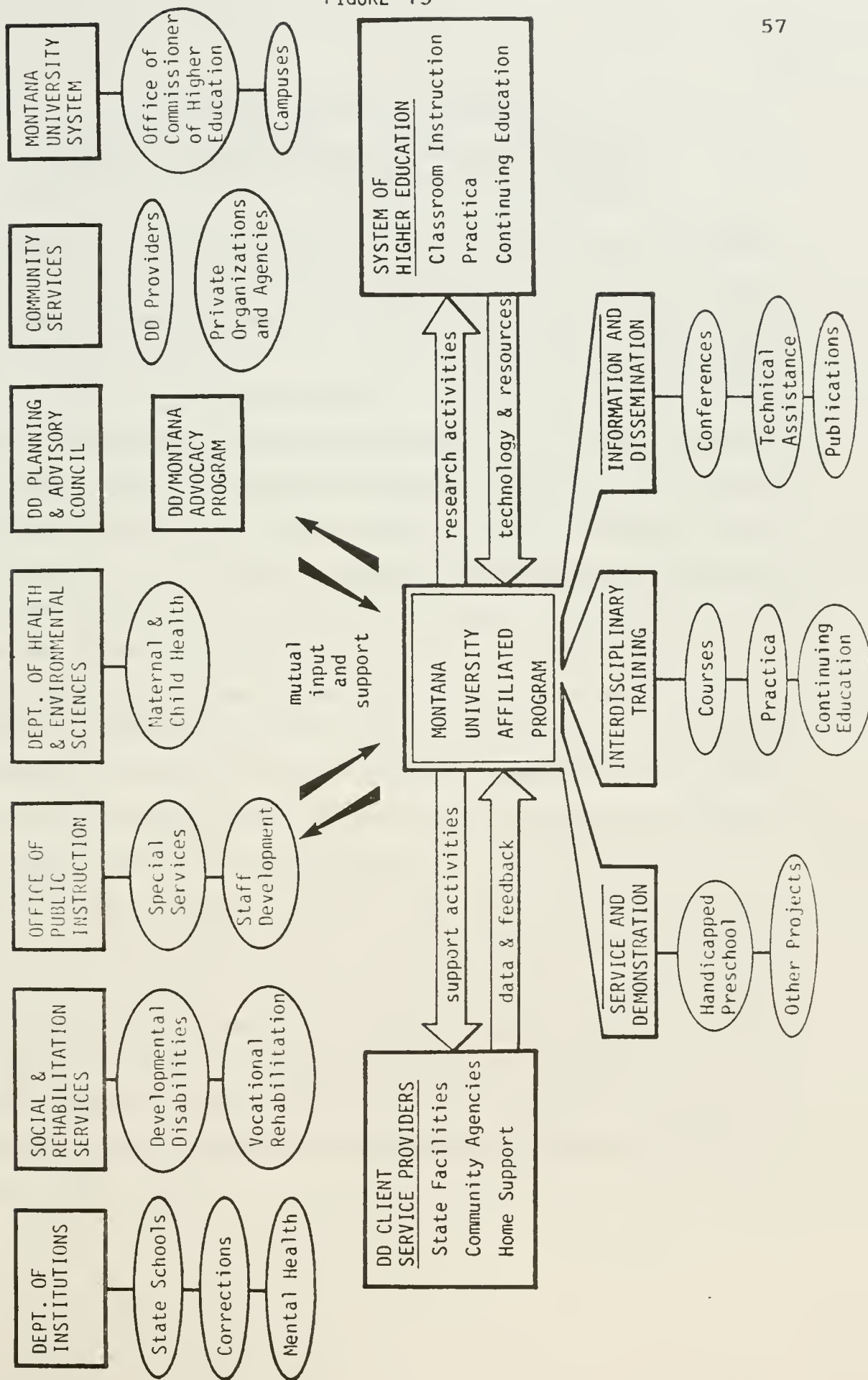


FIGURE 12

ROLE RELATIONSHIP OF MONTANA UAP WITH MONTANA SERVICE AGENCIES

FIGURE 13



INDIVIDUAL AND FAMILY SUPPORTS

A VISION OF INDIVIDUAL AND FAMILY SUPPORTS FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

All people and families need supports as an important part of their life experience: friends who can lend a helping hand, advisors and counselors who can help with work or personal problems, and people who can step in during an emergency to provide temporary assistance. Friendship and support are needed by everyone, regardless of their age or circumstances. The ideal support system is based on interdependence, enabling individuals and families to be mutually supportive as caring community members, with recognition that everyone has something to give. Informal supports--provided by neighbors, extended families, religious organizations, community volunteers--in themselves need support as the primary support resources to individuals and families. Formal supports and professionally staffed services need to be part of the available array of supports, including back-up to the informal support systems. Opportunities for recreation should also be available; access to leisure-time activities is an important support in itself because of its contribution to well-being. To be most helpful, supports must be responsive to individual differences, including life circumstances and cultural preferences. Communities themselves require supports to assist in their being a caring community and to promote interdependence and appreciation among community members with diverse backgrounds, interests and abilities.

Individuals with developmental disabilities have the same needs for supports as everyone else, although the supports may be needed more often, over a longer period, or in more life areas. A system of supports around the person with disabilities needs to be available rather than just a system of care. Being assisted with daily living tasks does not mean the person has sacrificed independence, so long as individuals can direct the provision of the supports in relation to their own needs and preferences. Supports need to be available to people of all ages with disabilities and to people with all types and levels of disability.

Families which include a person with a developmental disability also need access to supports which build on the family's existing supports and consider the needs of the entire family. The individual with a developmental disability or family members receiving supports should participate directly in the design, selection, control and monitoring of the supports being received. Supports that need to be available in every community include personal assistance; peer support; respite; assistance with service coordination/"case management"; advocacy; financial help for assistive devices, supplies, and home and automobile modifications; home aides; employment-related supports; counseling; transportation; and recreational opportunities. Supports to communities should also be available that promote greater understanding of the significance of independence, productivity and integration in the lives of people with developmental disabilities and that enhance community efforts to develop interdependent models of support with people with developmental disabilities and their families.

FACTS

Montana's developmental disabilities system of services for individuals and their families is premised on the assumptions that effective services are characterized by a balance of several living, training, and support elements that allow each individual the opportunity to exercise his or her fundamental rights. Training is one aspect of service delivery. Other aspects include a safe, homelike environment; supervision when necessary; recreation and leisure activities; nutritious and good tasting food; clean, appropriate clothing that fits; the dignity of risk; freedom to make choices; community integration, social support, friends, and opportunities for happiness.

Three million people with disabilities could benefit from community-based, publicly funded personal assistance in addition to the 850,000 who are already receiving it in some form, including help with personal maintenance and hygiene activities, mobility, household maintenance, childcare, money management, personal security, and communication services.

The majority of personal assistance programs do not emphasize consumer control (Litvak, Zukas, & Heumann, 1987).

According to the consumer survey, the predominant Personal Assistance Services utilized by persons with disabilities in Montana were Case Management, Information and Referral, and Homemaking Assistance (Table 2). Levels of satisfaction with those forms of assistance ranged from a low of 71% for Homemaking Assistance to 85% for Case Management. Surprisingly, only 21% to 28% of the consumers surveyed utilized Respite Care services, and only 10% received assistance from Family Support Groups. The level of dissatisfaction with those forms of support stemmed from the inadequacy of the funding for respite services, and the unavailability of Family Support Groups in rural areas of Montana.

Federal expenditures on behalf of people with developmental disabilities for institutional and facility-based services are much greater than for community-based supports to individuals and families. In FY 1988, federal expenditures for the ICF/MR program and large institutions (not including nursing homes) were over \$3 billion, almost four times greater than expenditures for community-based services and supports to individuals and families through the Social Services Block Grant program, regular Medicaid services, and services through the Medicaid Home and Community-Based Services waiver (Braddock, Hemp, & Fujiura, in press).

Since 1984, Montana expenditures for community-based supports have consistently exceeded expenditures for institutional facility-based services (Figure 14). In 1988, the total spending for community-based services comprised 58.8% of the total expenditures, contrasted with 41.2% directed to congregate care facilities.

Access to personal assistance services (PAS) improves the quality of life for people with disabilities. A recent survey found that 80 percent of those receiving such assistance reported a better quality of life since they had access to PAS; 64 percent that their level of independence and ability to do things inside and outside the home had increased; and

55 percent that their feelings about themselves had improved (Human Services Research Institute, 1989).

The majority of individuals with disabilities receiving personal assistance are people with a physical rather than a cognitive disability (Human Services Research Institute, 1989) and are age 60 or older (Litvak, Zukas, & Heumann, 1987). The number of people age 65 and older needing help in activities of daily living is expected to reach approximately 6.2 million by 1990 (Urban Institute, 1989).

The support most frequently available to people with developmental disabilities and their families is case management; approximately 350,000 individuals and families received case management services in relation to the presence of a developmental disability in FY 1988 (Braddock, Hemp, & Fujiura, in press).

From 31 to 41 million Americans annually have clearly diagnosable mental disorders, involving significant disability with respect to employment, attendance at school, or independent living (U.S. Congress, 1989). Adults with serious mental illness who participate in community support programs (CSP), however, are able to reduce their use of inpatient care by 50 percent; approximately two-thirds of CSP clients show improvement or stabilization in a one-year period (Manderscheid, 1987).

Many children with serious emotional disturbance--from 70 to 80 percent--are not receiving the services they need (Office of Technology Assessment, 1986). Over 5,000 such children are placed in out-of-state facilities, far from home and family (National Mental Health Association, 1988).

Supports available to families which include a person with a developmental disability are funded primarily with state funds. Total public expenditures for family supports exceeded \$170 million in 1988 and were reported as discrete budget items in 42 states. Supports included cash subsidies, respite, counseling, in-home therapies, home management assistance, peer support, specialized services and supplies, transportation, and architectural modifications. Many of the cash subsidy programs had been initiated over the past three years (Braddock, Hemp, & Fujiura, in press). States report, however, that there are many

more families who need supports than there are resources available (Lakin, Jaskulski, & Hill, in press).

Preliminary research on the child welfare system found that from 20 to 50 percent of children in foster care or child protective services because of neglect or about were children with some type of disability (Richardson, West, & Day, 1988).

One of the primary federal funding sources for individual and family supports, the Social Services Block Grant, has lost 50 percent of its "purchasing power" over the last ten years.

Most of the federal programs which currently finance supports are included in the administration's "flexible freeze" group in its FY 1990 federal budget request, including Supported Employment State Grants, Independent Living State Grants and Centers, the Social Services Block Grant, Children with Special Health Care Needs/Maternal and Child Health Block Grant, the Alcohol, Drug Abuse and Mental Health Block Grant, Title IV-B Child Welfare Services, the Foster Grandparent Program, Technology-Related Assistance Grants, Temporary Child Care and Crisis Nurseries Grants, and the Early Infant Intervention Program (special education). No funding is proposed for the Special Recreation Grant Program.

The increasing rate at which technology is impacting upon rehabilitation service delivery is overwhelming. In order to deliver the best possible service to clients, family training and case management staff and managers must make a tremendous effort to bridge the gap between knowing what is out there and applying that knowledge successfully (Elder & MacKinnon, 1988 [ICAART]). For service agencies, the environmental data fed into the service delivery process arises from consumers, other community agencies providing services, federal and state rules and regulations regarding handicapped persons' right to treatment, the numerous employee rights acts, and adaptive equipment technology sources and application methods. That provides one of the major challenges of today's service providers and the managers in the field of developmental disabilities. They must

harness the enormous wealth of information and efficiently utilize it in combination with the information they are generating to achieve maximum benefit for their consumers.

A recent survey of family trainers and case management providers in Montana indicates that more than 40% of them limit the type or number of objectives and activities they work on with children and families due to the paperwork involved. Almost 80% of the providers indicate that paperwork interferes with the time they need to work directly with families (Maloney, Bjorgen, & Hollingshead, 1989a). With the manager, the harried front-line providers may be aware of current technological advances in the fields of rehabilitation in the computer age. However, they generally do not have time to sift through the information to find applications and learn to use them in ways that would benefit the children and families they work with.

Social Services Block Grant: The Social Services Block Grant (SSBG, also known as "Title XX") provides federal funds to the states and territories to support a wide range of social services, including child protective and foster care services, homemaker and personal assistance services, counseling, case management, home-delivered meals, and socialization/recreation opportunities. If federal appropriation levels had kept pace with inflation, current funding would be \$4.1 billion rather than \$2.7 billion. Most states report that part of their SSBG allocation is used for services to people with disabilities (Office of Human Development Services, 1988a, 1988b). SSBG funds specifically identified by states as resources for services to people with developmental disabilities for FY 1988 were in the amount of \$207,082,206; all but \$1,223,200 of this was expended for community- rather than institution-based services (Braddock, Hemp, & Fujiura, in press). The FY 1988 total is almost \$46 million less than the \$253,037,391 reported for FY 1981, the year the Title XX program was converted to a block grant.

Medicaid/Home- and Community-Based Services Waiver: The Home and Community-Based (HCB) Services Waiver is used in many states to finance supports to individuals

and families. Federal expenditures for the program have grown from \$1.2 million in FY 1982 to over \$250 million in FY 1988. The number of participants (not including family members) has risen to over 29,000 (Braddock, Hemp, & Fujiura, in press). Federal policy requires that the waiver can only be used to fund services to people who would otherwise be in a Medicaid-funded institution and that Medicaid costs must not be greater with the waiver than they would be if waiver services were not available. Currently, all but 14 states participate in the waiver program with waivers that specifically include people with developmental disabilities; three of these provide similar services under the model waiver program. Many states use the HCB waiver to finance habilitation programs for people in the residential service system. Additional information may be found in the chapter on housing.

Carrying the concept of avoidance of out-of-home placement for children as far as possible, in 1983 Montana's state legislature approved the Title XIX Medicaid waiver known as the Specialized Family Care (SFC) waiver. In 1984, the first year of operation, approximately 35 children and families were provided with services. In September 1989, 101 children, 10% of the total children receiving services from the Division, were enrolled in the program, with 5.7% of the Division budget committed for services. See the Context of Services section for further discussion regarding SFC services.

Medicaid/Model Waiver Program: Some states have used the optional model waiver program to finance supports for individuals with severe disabilities and chronic health conditions--primarily children--to enable them to receive home-based care rather than be institutionalized. Federal expenditures for model waivers serving people with developmental disabilities rose in FY 1988 to \$3.1 million, up from \$55,000 in FY 1984. Each state can serve only a maximum of 200 people under this waiver. In FY 1988, a total of 359 people with developmental disabilities were served through model waivers in 11 states (Braddock, Hemp, & Fujiura, in press).

Medicaid/Optional Services: A variety of Medicaid service categories can be used by states to finance supports to individuals, including optional services such as personal care and mandatory services such as home health. Federal regulations require that services covered by Medicaid be based on medical needs and include medical supervision. In FY 1987, 21 states included personal care as a discrete optional service (Health Care Financing Administration, 1988). Medicaid funds are a significant resource to programs providing personal assistance services (Litvak, Zukas, & Heumann, 1987). Limits on service coverage, e.g., the maximum number of hours of service provided per month or year, are set by the individual states.

While Montana does not use any federal Medicaid dollars for targeted case management services, the state did utilize more than \$155 million in 1987 for expenditures for services and administrative costs for Medicaid, with only 4.5% of the funds used for administrative purposes.

Medicaid/Targeted Case Management: Many states use the Medicaid program to finance case management to Medicaid-eligible people with disabilities. As of July 1988 the targeted case management option had been added by nine states since it became an optional Medicaid service in 1986 (NASMRPD, 1988). Some states also finance case management services as a Medicaid administrative cost.

Medicaid/The TEFRA Eligibility Option: Provisions of the Tax Equity and Financial Responsibility Act of 1987 permit states to extend categorical Medicaid eligibility to children with severe disabilities and chronic health conditions who would otherwise only be eligible for Medicaid if they were hospitalized or in another institutional placement. Services funded may include individual and family supports; however, the services covered through this option are limited to those that are already part of the state's regular Medicaid service plan, which may or may not include adequate and appropriate supports. At the present time, 22 states have elected the TEFRA option (NASMRPD, 1989).

Medicare: The Medicare program permits some financing of individual supports; however, these are limited to health-related services, generally in connection with an episode of hospitalization for an acute illness. (See the chapter on health for additional information.)

Centers for Independent Living: Parts A and B of the federal Independent Living Program provides formula grants to states for the promotion of independent living among people with severe disabilities and grants to individual independent living centers (ILCs), respectively. There are currently over 170 ILCs nationwide funded by Part B grants (Rehabilitation Services Administration, 1988). Funding for ILCs may come from Part A as well, as a minimum of 20 percent of the state's Part A grant must be "subgranted" to community-based programs. The overwhelming majority of ILCs provide services to people with orthopedic impairments, including cerebral palsy (83 percent of ILCs), spinal cord injury (79 percent) and muscular dystrophy (74 percent); approximately 59 percent include eligibility for people with mental retardation, 85 percent for people for people with visual impairment, compared to only 30 percent which include people with mental illness (Nosek, Roth, & Zhu, 1988).

Technology-Related Assistance for Individuals with Disabilities: This program was authorized in 1988 (P.L. 100-407) to provide grants to the states to assist them in the development and implementation of consumer-responsive statewide systems of technology-related assistance. The goal of the program is to promote the independence and productivity of people with disabilities by expanding the availability of the benefits of new technology in assistive devices. Ten states are proposed to receive grants on a competitive basis during FY 1989, 20 in FY 1990, and the remaining during FY 1991. Implementation of the program, however, is subject to federal appropriation levels. The program is included in the Administration's "flexible freeze" group in the FY 1990 budget request.

Child Welfare Services/Foster Care: Both Titles IV-B and IV-E of the Social Security Act provide federal funding to state child welfare systems to support foster care. Title IV-B funds have the goal of helping families remain intact and helping families reunite when situations have necessitated a period of foster care for the children. Title IV-E foster care funds are used to provide payments to foster parents and to finance related staff training and administrative costs. Federal funding to the states under Title IV-E in FY 1988 was \$716.3 million, of which \$422.0 million was for payments to foster parents. Total IV-B funds to states in FY 1988 were \$239.4 million, including \$5.1 million transferred to IV-E foster care programs under special provisions related to the states' total child welfare allocation. The estimated average of children in foster care each month during FY 1988 was 122,949 (Committee on Ways and Means, U.S. House of Representatives, 1989). Many children with disabilities receive foster care through the child welfare service system.

Child Welfare/Adoption Assistance: Title IV-E also provides funds to states for adoption assistance and to recruit and assist families who adopt children with disabilities ("special needs adoptions"). State claims for adoption assistance are expected to rise to \$111.7 million in FY 1989, up from \$54.8 million in FY 1986; the estimated average monthly number of children benefitting from this program in FY 1989 is expected to exceed 38,000 (Committee on Ways and Means, U.S. House of Representatives, 1989).

Older Americans Act: Title III of the Older Americans Act funds a variety of support services to people age 60 and older, including supports provided at designated senior centers and those provided in the home. Services include counseling, home health, recreation, transportation, home modifications for older people with disabilities, meals, and information and referral services. Federal grants are distributed to state agencies on aging on a formula basis to finance these services. Part D of Title III authorized an additional allocation to states for in-home services to older people with Alzheimer's disease

or a related disorder, as well as supports to family members caring for such individuals. Approximately 8.6 million older individuals received support services funded by Title III grants in FY 1987; 2.8 million participated in the congregate meals program (i.e., in senior centers or congregate living facilities) and approximately 729,000 received meals in their home (Administration on Aging, 1988).

Alcohol, Drug Abuse and Mental Health Services (ADM) Block Grant: The ADM block grant provides federal funds to states on a formula basis for mental health, alcohol abuse, and drug abuse services, as well as services to reduce the transmission of AIDS/HIV infection by intravenous drug users. The mental health portion of the block grant must be used by the states to finance grants to community mental health centers, which in turn must provide at least a basic core of services (outpatient, partial hospitalization/day treatment/psychosocial, screening of potential state hospital admissions, emergency services, and consultation/education). A minimum of 10 percent of the total mental health portion must be allocated for services to children. For both the children's portion and the remainder, an overall minimum of 55 percent must be used to develop and provide new community mental health services and programs by 1991. The total mental health portion in FY 1989 rose to \$246,680,017 as compared to \$238,234,006 in FY 1988. Because of changes in the ADM block grant allocation formula, however, the dollar amount of the mental health portion decreased between FY 1988 and FY 1989 in 38 states.

Although the literature provides little in the way of "hard statistics" as to the prevalence of substance abuse or alcoholism among persons with developmental disabilities, recent studies are consistent in finding that alcohol problems are no less for this population than for the general population. (DiNitto & Krishef, 1983; Krishef, 1986; Westermeyer et al., 1988). This is especially true as the deinstitutionalization movement has provided full participation in the activities of the larger community. Along with this participation in the community has come the access to a number of previously inaccessible activities, including the consumption of alcohol.

As a result of accessibility to alcohol, it is becoming evident that persons with developmental disabilities do drink and suffer from alcohol-related problems (Rehab Brief, 1982). Having been removed from a structured environment and placed in the mainstream of the community, these individuals are now experiencing the stress of having to make their own personal choices and decisions. They are also finding that this stress, in addition to conflicts and fears, can be disguised or relieved through drinking (Selan, 1979). Managing stress, resolving conflicts, dealing with fears, and developing socialization and decision-making skills are all areas of need which can be impacted through the use of education, thus reducing the chance that the individual will turn to alcohol or other drugs to solve life's problems.

In March, 1988, all twelve Training and Contract Managers (TCMs) within Montana's Developmental Disabilities Division (DDD), as well as seven group home program managers, three social work supervisors and five case managers were surveyed by Project ADAPT. Over ninety percent of the individuals contacted felt that there was a problem of such severity that it needed to be addressed. The reported incidence of alcohol-related problems among independent and transitional living persons with developmental disabilities ranged from ten to thirty percent. In addition, there were reports of individuals living in group home situations who were also suffering from alcohol-related problems. A number of respondents stated that the traditional methods of dealing with such problems had not proven successful (Bjorgen, 1989).

Mental Health Demonstration Programs: Many states have received federal grant funds from the National Institute of Mental Health under the mental health demonstration programs. Federal grants to states have been available since 1977 to develop services for adults with long-term serious mental illness using the community support program (CSP) model. This approach emphasizes community-based services supports to individuals and family members, and consumer involvement. Since the program's inception, all states, Puerto Rico and the Virgin Islands have received at least one federal CSP grant, with total

federal funding of \$56.3 million. In FY 1988, grants were awarded to 23 states, for a total federal expenditure of \$10.4 million (Jaskulski & Robinson, 1988). The Child and Adolescent Service System Program (CASSP) provides grants to states to develop improved mental health services for children with serious emotional disturbance. Since the program's inception in 1983, 39 states and the Virgin Islands have received federal CASSP grants. In FY 1987, grants were awarded to 30 states, including both new and continuation awards, for a total federal expenditure of \$4.06 million. Separate demonstration grants for mental health service development and improvement are available to states to meet the needs of elderly individuals with serious mental illness, young adults with both serious mental illness and substance abuse problems, and homeless individuals with serious mental illness.

McKinney Act Block Grant: Programs for people who are homeless authorized by the McKinney Act include grants for mental health demonstration projects, as noted above, and a block grant to the states to assist them in the financing of outreach, case management, and mental health treatment services to homeless individuals with serious mental illness. Federal funds were first allocated to the states late in FY 1987. Federal appropriations for the "Homeless Mentally Ill" Block Grant declined from a combined total of \$43.7 million for FY 1987/FY 1988 to \$14.6 million in FY 1989.

Special Recreation Program: The Rehabilitation Services Administration of the Department of Education funds grants to states, public agencies, and non-profit organizations to help finance the development of recreational activities for people with disabilities. The programs are expected to emphasize community integration opportunities and activities that help promote independence. In FY 1987, 30 projects received two-year grants under this program; the FY 1987 appropriation was \$2.33 million, including program administration by the federal government. The appropriation rose to \$2.62 million in FY 1989; however, the Administration has not included any funds for the program in its FY 1990 budget request.

Special Education for Infants and Toddlers: The Early Infant Intervention ("Handicapped Infants and Toddlers") Program provides funds to the states to plan, develop and implement a statewide system for early intervention services with disabilities to children from birth to two years of age and their families. Services are to be family-centered, coordinated, and community-based, and may include supports such as training for parents in ways to enhance their child's development. (See chapter on education for additional information.)

Children with Special Health Care Needs: The Maternal and Child Health Block Grant program includes funds to the states for the Children with Special Health Care Needs (CSHCN) program. These federal funds are to be used to promote the development of community-based service networks and case management services for children with special health care needs and their families. (See chapter on health for additional information.)

Temporary Child Care and Crisis Nurseries for Children with Handicaps and Chronic Illnesses: This program was authorized in 1986 (P.L. 99-401) to fund demonstration grants to states to assist governmental and private organizations in the provision of in-home or out-of-home temporary, non-medical care for children with disabilities or with chronic or terminal illnesses. Several states received federal grants in FY 1988, with a federal funding appropriation of \$4.787 million including federal administrative costs. The program is included in the Administration's "flexible freeze" group in the FY 1990 budget proposals.

Foster Grandparents Program: This program provides federal grants to state and local governments and non-profit organizations to finance part-time volunteer service opportunities as "foster grandparents" for people over age 60, primarily low-income. The volunteer work funded through the project is with children who have a developmental disability and other special needs children. The program is administered by ACTION, the federal domestic volunteer agency, along with the Senior Companion Program, which has

also been used to support volunteer work with people who have a developmental disability. In FY 1987, 19,000 volunteers worked with 66,000 children; as many as 10 million children are estimated to be able to benefit from the program if additional resources were available. The \$2.20 per hour stipend paid to the low-income volunteers has not risen since FY 1985. The program is included in the Administration's "flexible freeze" category for FY 1990.

CRITICAL ISSUES

The overriding issue is the relative lack of resources for supports to individuals with developmental disabilities and their families despite their critical importance to the promotion of independence, productivity, and community integration.

A related issue is the bias in many publicly-supported programs toward funding services in facilities and institutions, but not in homes and communities. Although efforts to reduce this bias have led to the development of programs such as the Medicaid Home- and Community-Based Services Waiver and the Technology-Related Assistance Grants, these programs are generally at state option, limited in availability, and funded at significantly lower levels than facility-based services. This is especially the case for services that are "non-medical," such as personal assistance to people with disabilities that enable them to live independently and to maintain competitive employment.

Social Changes/Demographic Issues

There is an increasing number of people with functional limitations in their activities of daily living, especially associated with the significant growth in the number of people who are elderly. There is no corresponding rate of growth in the availability of supports to individuals.

More and more mothers are working. The proportion of working mothers is expected to reach 68 percent in 1990, compared to 30 percent in 1960 (citation pending). Coupled with the large increase in the number of single-parents, this indicates a related increase in the need for family supports, also unmatched by increased availability.

Policy Issues: Programmatic

For both individual and family supports, there is frequently a lack of involvement and focus on the consumer. Individual supports are seldom available that can be directed by the person with the developmental disability or selected from an array of supports to provide a "package" of supports tailored to the needs and preferences of the individual. Reinforcement of the emphasis on consumer control in the Independent Living Program is still awaiting publication of the federal performance standards. Family supports tend to provide somewhat more flexibility, such as those available through a cash subsidy program. Overall, however, there is little family input in the design and monitoring of family support programs.

In 1988, the Montana University Affiliated Program Satellite (MUAPS) surveyed all families receiving Child and Family Services (CFS) in Montana. Survey results from 359 families (65%) indicate that a majority of the families served had significant involvement in the selection of activities and supports needed, with 76% indicating agreement with that perspective. With 24% expressing uncertainty or disagreement with that premise, it is not surprising that 23% of the respondents indicated a desire to be more involved in the service planning process in response to a follow-up question (Maloney, Bjorgen, Hollingshead, 1989b).

Federally-financed supports to individuals and families tend to be tied to medical care needs because of their basis in health finance programs. For example, "personal care" services provided through the Medicaid program are defined as "medically-oriented tasks having to do with a patient's physical requirements," must be prescribed by a physician and supervised by a registered nurse, and be in accordance with the recipient's "plan of treatment" (Health Care Financing Administration, 1979). Although the new Medicare Catastrophic Coverage Act includes some provisions for family supports (80 percent reimbursement for up to 80 hours per year of in-home care for persons who are "chronically dependent"), basic Medicare coverage reimburses only for services that are

reasonable and necessary for the diagnosis and treatment of an illness or injury, and excludes coverage of assistance in activities of daily living.

Almost none of the supports to individuals with developmental disabilities and their families are considered entitlements. Most federal funding that is available is at state or local option, including Medicaid waivers, optional services, and extension of Medicaid eligibility to children with disabilities who would otherwise only be eligible if they were institutionalized; and discretionary grants for "demonstration" programs and special recreation programs, independent living centers, community support programs for people with serious mental illness, and the development of statewide systems to make assistive devices and services available.

The community mental health system has not developed adequately to meet the needs of adults with persistent and serious mental illness who would previously have been long-term patients in state mental institutions, despite the proven effectiveness of the community support program model. Services for children with serious emotional disturbance are frequently limited to out-of-home placements, in many cases to facilities in other states, with little or no availability of community-based care and supports to families.

Policy Issues: Access/Eligibility

The potential benefits of the Medicaid Home- and Community-Based Services (HCB) Waiver are limited by the "cost-neutrality" requirement which prevents states from using the HCB waiver to finance home- and community-based supports to all people with developmental disabilities who need them. In addition, the waiver is not available in all states.

Access to suppose financed through the general Medicaid program is limited by several factors:

- Medicaid does not cover over 60 percent of the low income population;

- Some states have no provision for waiving parental income in extending Medicaid eligibility to children with developmental disabilities who remain in their family home;
- Some states have categorical Medicaid eligibility requirements that are even more restrictive than federal SSI eligibility criteria;
- Individual state regulations on coverage may limit Medicaid reimbursement to an inadequate number of units of support services;
- Low levels of reimbursement for Medicaid vendors may discourage provider participation and reduce the availability of supports.

There are gaps reported across the nation in the availability of supports to individuals with developmental disabilities and their families living in rural areas, supports for consumers with the most severe disabilities, and supports that can be obtained in an emergency.

The 1988 Montana UAP survey of CFS services found that the most severe gaps in services and supports were in the areas of availability of a crisis line to call in emergencies, information regarding insurance, and help for families dealing with stressful situations (Maloney, Bjorgen, & Hollingshead, 1989b).

Many Independent Living Centers (ILCs) restrict services to people with only certain kinds of disabilities. Over 40 percent do not serve people with mental retardation, and 70 percent do not serve people with mental illness.

Many older people with developmental disabilities find it difficult to obtain services in the programs funded through the Older Americans Act.

Policy Issues: Fiscal/Resource

Limited funding is available for home- and community-based supports to individuals with developmental disabilities and their families. Expenditures for supports are consistently much lower than those for institutional and facility-based care, despite the fact that these expenditures broaden the availability of services to many more people than the facility-based programs that serve relatively few individuals.

The Social Services Block Grant, a major source of funding for supports to individuals with developmental disabilities and their families in many states, has been significantly underfunded for the past several years in comparison to its original authorization levels. Current legislative proposals to increase federal appropriation levels will provide only partial restoration.

In the current era of deficit reduction, increased costs for existing facility-based services, such as those provided in large state institutions, frequently leave few resources for individual and family supports--without regard to their relative cost-effectiveness and their significance in the promotion of independence, productivity, and community integration.

Policy Issues: Data/Monitoring/Accountability

The individuals with developmental disabilities who receive supports are inadequately involved in their monitoring and supervision.

There is an overall lack of data on the needs and preferences of individuals with developmental disabilities for various kinds of supports and their relative significance in helping people reach greater levels of independence, productivity and community integration.

There is almost no current information available on the federally-supported Independent Living Program regarding services being provided and the characteristics of those being served.

Despite its critical role in financing supports to individuals with developmental disabilities and their families, there is no data available on Medicaid services and expenditures in this area other than broad estimates. There is no recent national data on the way the HCB waiver program is being used by the states nor any separation of data on expenditures for people in state-sponsored residential care programs vs. those for people living in their own homes, despite the critical need for information on the potential of this approach in financing such supports.

There is a lack of data on the services being provided to children with serious emotional disturbance, including some states which were unable to report even the total number of such children who had been placed out-of-state. Although services to adults with serious and persistent mental illness are a priority in many states, there is no systematic data collection on public expenditures for these services.

Few data are available on supports provided to people with developmental disabilities through "generic" support programs such as child welfare and aging services, primarily because of the lack of reporting requirements that would include such information. This issue has been partially addressed for some programs with recent legislation that requires state reports on the Social Services Block Grant to indicate the number of people with disabilities who received services funded by the block grant, and new reporting requirements for Title III of the Older Americans Act to include effectiveness in targeting services to people with impairments in physical or mental functioning. There are no requirements, however, that specify reports on services to people who meet the federal developmental disability definition.

The literature provides little in the way of hard data regarding the prevalence of substance abuse or alcoholism among persons with developmental disabilities. However, recent studies consistently find that alcohol problems are no less for this population than for the general population. Further analysis in this problem area must be done, with more efforts applied to prevention and treatment as necessary.

Public Attitudes

There is a need for an overall shift in thinking from facility-based services to a "facility-free" system of supports. To accomplish this, public attitudes will need to include recognition of the significance of this approach in the quality of life for people with developmental disabilities and the viability of this approach for people with challenging and severe disabilities.

There is a lack of supports to neighborhoods, individuals, informal organizations and communities to enable them to participate in the support network for people with developmental disabilities.

NADDC RECOMMENDATIONS

1. Supports to individuals with developmental disabilities that promote their independence, productivity and integration in the community should be a major policy goal in the 1990s, embodying the following principles:
 - * Maximum consumer control and direction
 - * Priority for community-based services
 - * Availability to people in all areas, of all ages, and with all types and levels of disability
2. Supports to families which include a family member with a developmental disability should also be a priority in the 1990s, with emphasis on supports that:
 - * Reinforce the primary role of families in providing care and support to younger people with developmental disabilities and their ongoing role as part of the support system for adults with developmental disabilities
 - * Involve families in the design, implementation and monitoring of family support systems
3. The availability of supports to individuals with developmental disabilities and their family members should not be limited to "medically necessary" services; public funding of supports should not be governed by health care finance requirements that favor medically-related and facility-based care. Medicaid restrictions on the financing of home- and community-based supports must be lifted in ways that stimulate their expanded availability to people with developmental disabilities across all the states, regardless of the nature of the developmental disability.
4. Federal funding for the Social Services Block Grant should be increased, as proposed in the Social Services Block Grant Restoration Act of 1989 (S. 704); proposals to earmark increased SSBG funding for specific services, rather than

maintain state flexibility in the use of these funds to meet state-defined priorities in social services, are not recommended.

5. Funding levels for discretionary programs that stimulate the development of supports, including grants for recreation programs, assistive devices, community support systems in mental health, temporary child care/crisis nurseries, and independent living centers, must be maintained--and expanded where possible. These programs should not be sacrificed to the budget crisis while expenditures for more costly facility-based services continue to increase.
6. Coordination assistance ("case management") must be available to individuals with developmental disabilities and family members to facilitate arrangements for supports and their monitoring. Sufficient funding must be available to permit small enough "caseloads" for effective help with coordination; additional resources must be available for systems-level coordination.
7. Comprehensive education efforts should be undertaken to help translate the concept of a facility-free support system into reality, including:
 - * Supports to the participation of communities, neighbors and informal organizations
 - * An orientation for professionals in the service system to assist them in providing supports to individuals with developmental disabilities, family members, and communities
 - * Information from the consumer perspective on the significance of supports
8. The revived interest in reports on federal expenditures, such as the recently enacted requirements for state reports on Social Services Block Grant expenditures, should be expanded to provide additional information on how supports are financed and the availability of supports to people with developmental disabilities. This information should be complemented by consumer-based research on the relationship between supports and the ability to reach greater independence, productivity and community integration, building on the consumer survey undertaken for the 1990 Report.

MONTANA RECOMMENDATIONS

The primary source for Montana's recommendations is the Temple University Consumer Survey conducted by our state in 1989. Recommendations derived from the survey are followed by parenthetical reference to specific item numbers in the survey, indicating the percent of respondents dissatisfied with a particular service and the total number of respondents to that particular item. If the issue also arose during the public forums, that source is noted in the parenthetical reference as well.

1. Adequate case management services and information and referral procedures should be increased, assuring integration of clients into regular services, and providing respect for the client's dignity (Items 1.2 & 1.3: case management - 16.7% of 72; I&R - 26% of 54).
2. Funding and assistance for architectural modifications which adapt individuals' living, work, learning, or recreational environments to make them more accessible or functionally useful should be increased (Item 2.14: 25% of 8).
3. Funding and availability of providers for respite or attendant care services need to be increased. The assistance available should be more appropriately individualized to suit clients' needs (i.e., individual is behaviorally challenging, medically fragile) (Item 6.1: respite care - 16.7% of 24; attendant care - 66.7% of 6; funding for in home respite - 24% of 25; funding for outside home respite - 25% of 20).
4. Behavior management assistance or training should be increased, with services adequately staffed with skilled professionals to meet the demand for such assistance (Item 6.3: 29.6% of 27).
5. Community living assistance or training for persons with disabilities must be increased (Item 6.10: 16.7% of 18).
6. Funding for adaptive equipment and assistive devices should be readily available so that currently prohibitive costs for the equipment do not constrain individuals

to choose to live less than normalized lives despite the availability of technologically advanced devices (Item 6.12: 17.9% of 28).

7. Food assistance/food stamps must be made increasingly available in a manner adapted and individualized to accommodate the clients' needs (Item 6.14: 29% of 31).
8. Service workers within social service systems such as the Department of Family Services need to be provided structured, systematic cross-training regarding disabilities, services for persons with disabilities, and related issues. Their caseloads should be appropriately adjusted in order to provide adequate assistance to persons with disabilities (forums).
9. Development of family self-help support groups which adequately meet their needs should be encouraged and supported (Item 6.18: 18.2% of 11).
10. Integrated child day care services must be increased, adapted and individualized to meet the needs of children with disabilities (Item 8.3: 27% of 11).
11. Recreation and leisure resources need to be developed, adapting existing resources or creating new services. The resources must be integrated and individualized for persons with disabilities and be available at a reasonable cost (Item 9.2: 41% of 58).
12. Further analysis of the prevalence of substance abuse or alcoholism among persons with developmental disabilities is necessary, with more funding and efforts applied to prevention and treatment.
13. A great need exists for systems development which will employ state-of-the-art computer technology and artificial intelligence applications to harness the enormous wealth of information from national sources and efficiently utilize it in combination with the information generated in applied settings to achieve maximum benefit for consumers.

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APPENDIX C

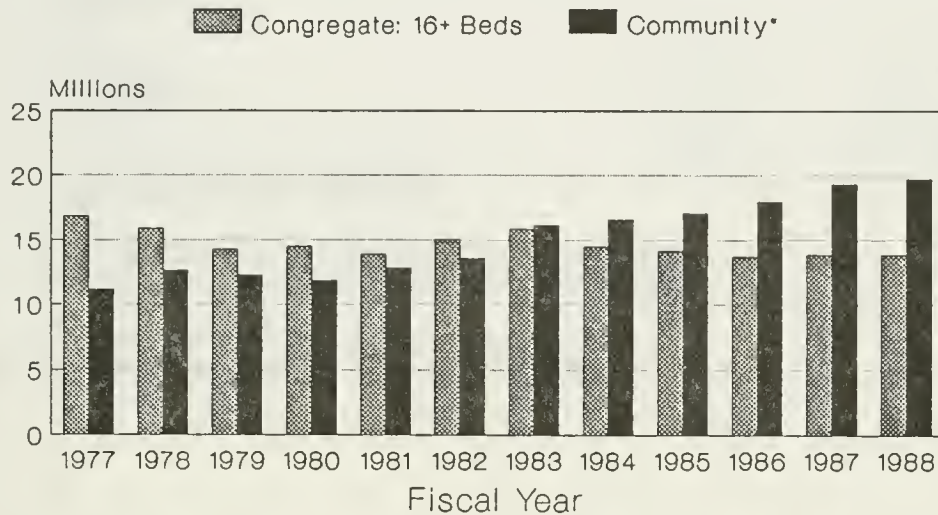
FIGURES AND TABLES

Level of Satisfaction with Services - IFS

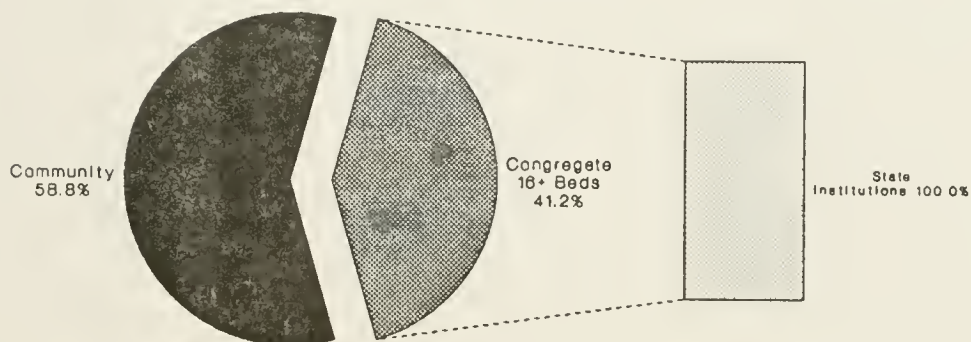
<u>Service</u>	<u>Percentage of Participants Receiving Services</u>	<u>% Satisfied of those Receiving Services</u>	<u>% Dissat. of those Receiving Services</u>
<u>Case Coordination</u>			
Assessment/IHP	86%	86%	11%
Case Management	83%	85%	10%
Information & Referral	60%	76%	10%
<u>Residential Services</u>			
Substitute or Foster Family	23%	100%	-
Homemaking Assistance	71%	71%	14%
Architectural Modifications	8%	75%	38%
<u>Individual Support Services</u>			
Mental Health or Counseling	15%	6%	27%
Physical Therapy	36%	80%	6%
Communications & Language Services	46%	82%	11%
<u>Caregiver Support</u>			
Respite Care (Inside Home)	28%	78%	15%
Respite Care (Outside Home)	21%	71%	24%
Family Support Groups	10%	80%	20%
<u>Other Services</u>			
Recreation/Leisure Services	67%	62%	23%

MONTANA

Adjusted MR/DD Spending for Congregate Residential & Community Services



* Includes 15 Bed or Less Residential & Other Community Services



FY 1988 Total Spending:
\$33.7 Million

Source:
University of Illinois at Chgo UAP, 1989

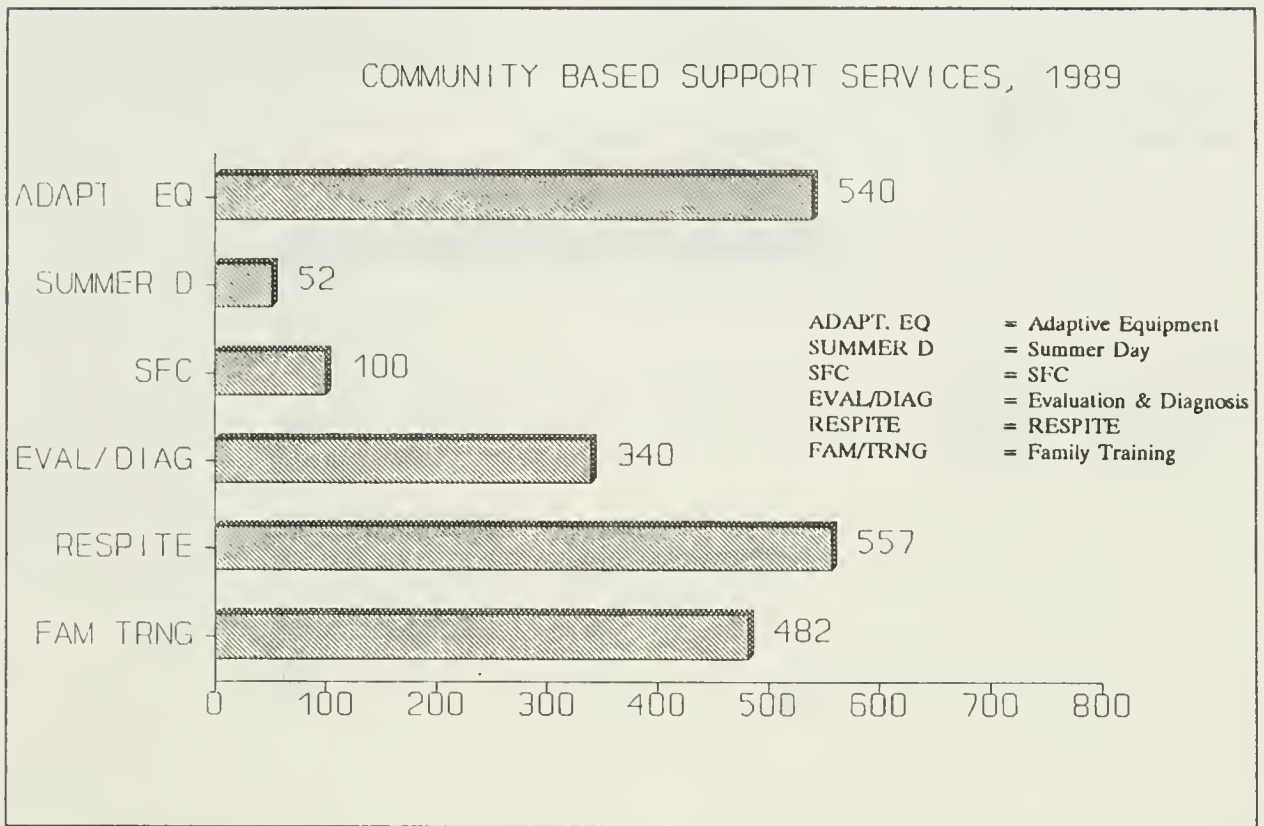


FIGURE 15

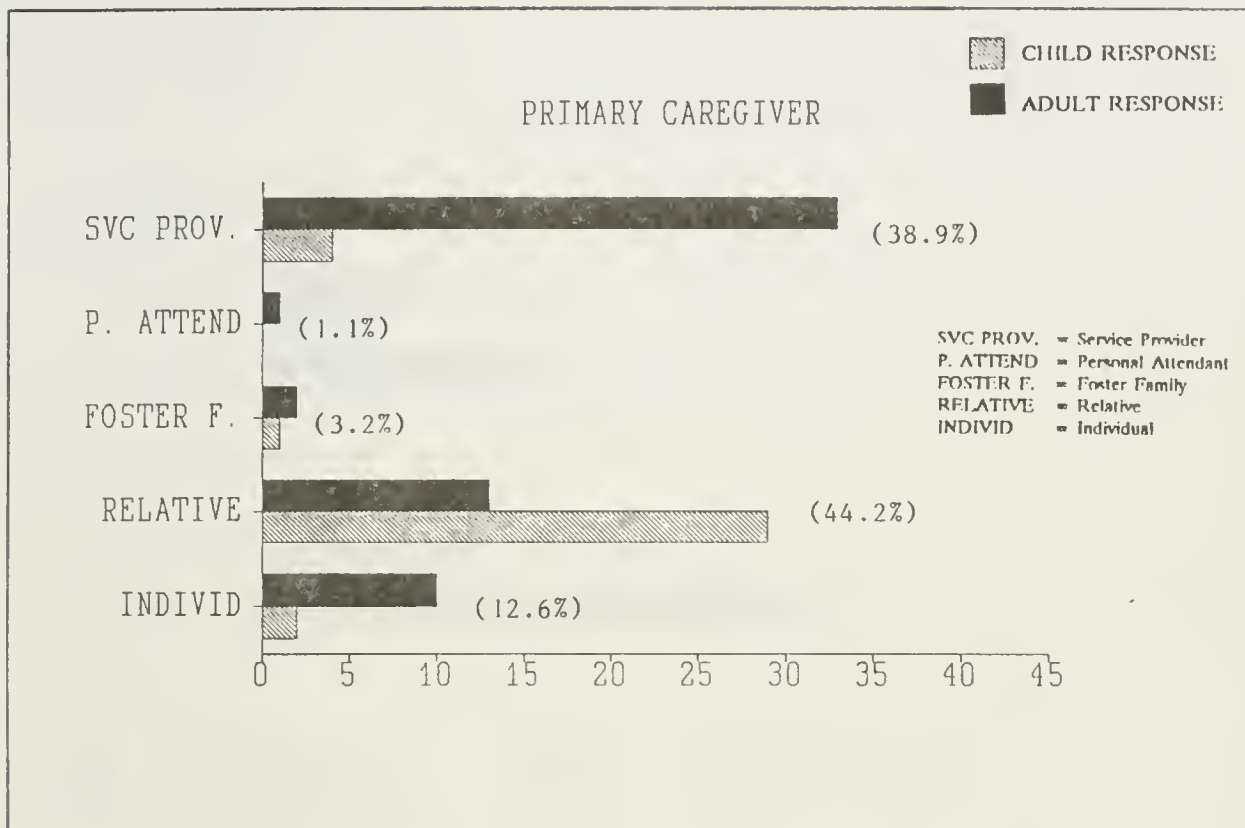


FIGURE 16

Consumer Survey 1989

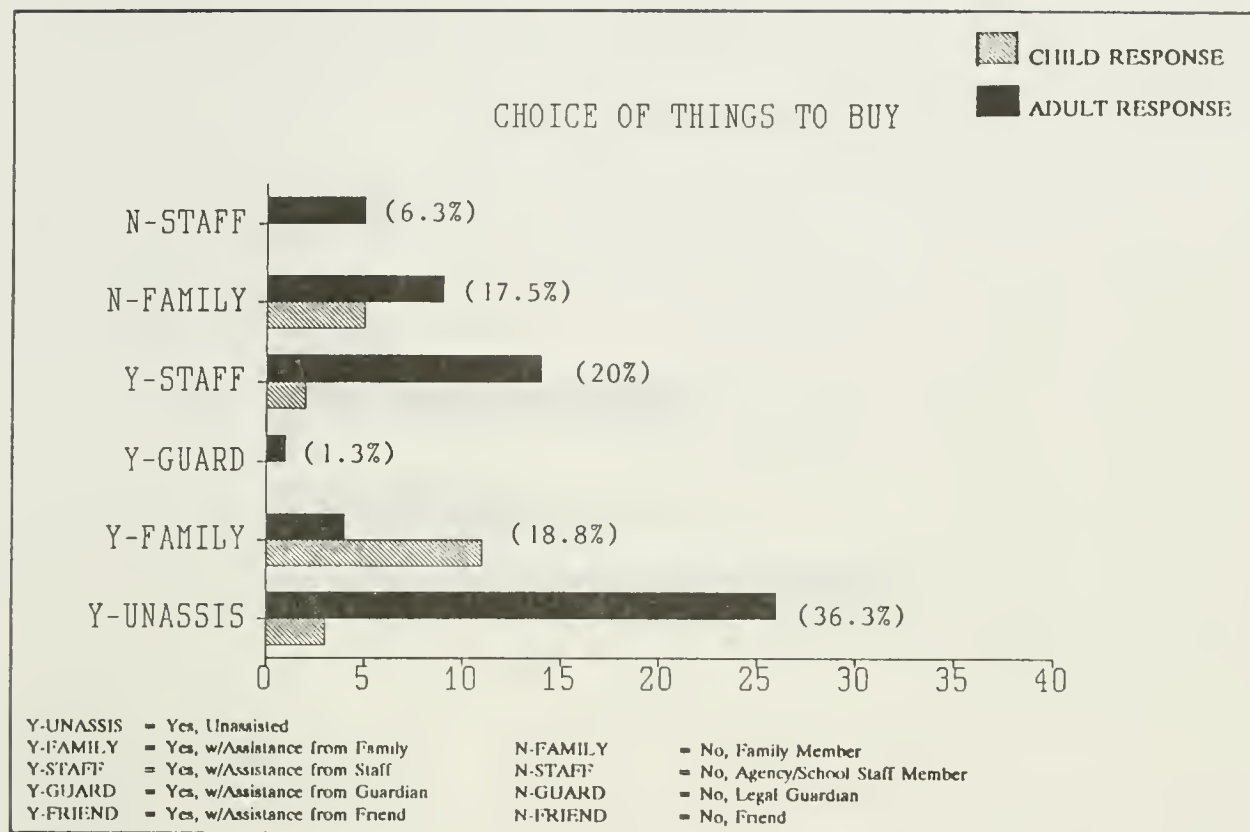


FIGURE 17

Consumer Survey 1989

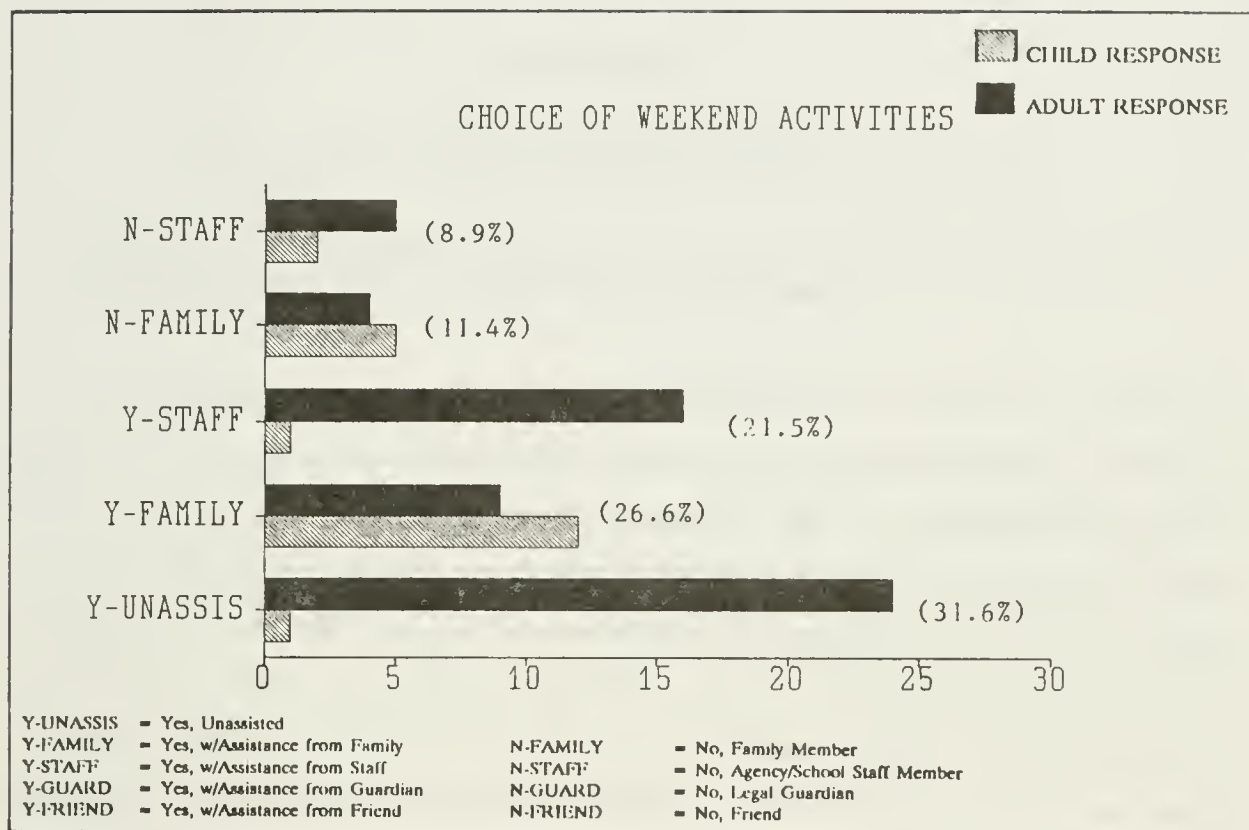


FIGURE 18

Consumer Survey 1989

EDUCATION

A VISION OF EDUCATION FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

What the best and wisest parent wants for his own child, that must the community want for all of its children. (John Dewey)

The ultimate goal of American public education is to prepare its students to participate in the life of our democracy as informed, contributing citizens. A vision of public education in America is to provide youngsters with the understanding of their common heritage as well as the diversity from which it springs. Public education is based on the premise that to exercise the responsibilities of citizenship in a democratic society, the people must have certain basic knowledge about our country and the world. To successfully achieve these goals, schooling must expose students to a panoply of experiences, learning and social, to prepare them for adulthood in a complex and varied society. Acknowledgement for educational achievement must be based upon outcomes, and not on race, sex, age, or disability of the student. At an appropriate stage in the educational process, vocational interests and potential must be explored and addressed. This vision presumes that all people, including those with developmental disabilities, can learn and develop.

It should be acknowledged that each learner has a certain "style" of learning, characteristic behaviors for perceiving, analyzing, and responding to learning situations, and a distinct set of needs, as well as strengths and weaknesses. Curricula and teaching methods need to be individually designed for each student, based on his/her unique learning needs. However, this should not result in schools which attempt to meet the needs of some of these individuals in segregated environments. Classroom organizational techniques, varying instructional programs and methods, as well as the universal teaching skills of providing quality education are all components of public education, which enable

student educational experience that is "special" - one that pays the utmost attention to everyone's individual needs in the most socially integrating way possible.

Schooling must also be preparation for life in general, exposing youngsters to the variety of American society they will be expected to deal with as adults. Independence, productivity, and integration into our educational frameworks are essential to maintain such a vision. By fostering independence, schools validate that every individual is capable of growth, and will eventually participate in adult society. Productivity builds upon independence by helping to ensure that individual interests and abilities are explored, in order that their eventual move into adult society is a meaningful one. Finally, integration ensures that schools will help to prepare individuals for adult society and to exercise citizenship and community involvement.

Parents want educational opportunities for their children including day care, early education (pre-school), kindergarten through grade twelve, vocational education, as well as post-secondary educational experiences. These are universal goals, encompassing the aspirations of those with and without disabilities. Everyone must be able to benefit from the acquisition of knowledge and skills and to be educated in a way that is functional in society to allow all people to actively participate to the best of their abilities.

This vision for all youngsters in American society has not been achieved, particularly for those with developmental disabilities and intervention to correct the situation is required. Individuals with developmental disabilities and their families want to enjoy the same benefits that the acquisition of knowledge offers to those without disabilities. They want to be provided every educational opportunity to do so. This vision challenges us to find ways that each person can learn and, therefore, to become contributing adults. Not only must our vision be expanded to benefit the general population, it must include the supports needed by students with developmental disabilities. Landmark legislation, the Education of All Handicapped Children Act (P.L. 94-142) had the intent of removing barriers to educating youngsters with disabilities. While much progress has been made,

that intent is far from realized. It is time to shape our educational service system into that which was envisioned by P.L. 94-142.

People with developmental disabilities in many cases require special supports in order to fully benefit from public education. It is necessary for special supports to "follow" an individual with developmental disabilities into the least restrictive - or most integrated - settings. The individual should not have to change before he or she can take part in the most integrated setting, but rather the emphasis should be on changing the special supports so that he or she can take part in the setting.

Those special supports which are aimed at helping to meet individual learning needs include individualized instruction, adaptive equipment and time for mastery. Some individuals with developmental disabilities may learn more slowly than their peers without disabilities, and will need curricula and teaching methods which allow time for mastery, and time to recheck and solidify this initial mastery to ensure that the knowledge can be transferred from one situation to another. Other supports include technological aids, transportation and accessible buildings. Necessary technological aids might include ceiling projectors for those in bed or gurneys, automatic page turners, or augmentative communication systems. Some individuals with disabilities will need specialized transportation services, such as lift buses that can accommodate wheelchairs. In making buildings accessible, several provisions such as ramps, nonskid surfaces, or other environmental modifications can enable independence.

One support for ensuring that educational programs meet the individual learning and environmental needs of students with disabilities is the development of an individualized education program (IEP), which involves the cooperation of a multidisciplinary team, including the parent(s) or guardian(s) of the individual with disabilities (and sometimes the student, if appropriate). The IEP documents the individual learning needs of the student, the types of educational and related services which will be provided to meet these needs, and the least restrictive educational environment in which services will be delivered.

CRITICAL ISSUES

Challenges in Educating Students with Disabilities in Montana

Montana has a total of 546 public school districts, but only 774 schools, so it is not surprising that one-school school districts are the vast majority. There are 114 one-room schools and 158 schools with less than three teachers. Of the latter, 95 have one teacher only and the other 63 have only another teacher or aide (Office of Public Instruction, 1989). With the school population of 152,207 spread out over an enormous geographical area, 86 percent of the school districts are considered rural. With schools of that size, teacher preparation, knowledge of curriculum and instruction, and a supportive network of colleagues becomes imperative for the provision of appropriate educational experiences to all students, particularly students with disabilities (Putnam, 1989).

Montana Code Annotated, 1985

*** 20-7-411. Regular Classes Are Preferred—Obligation to Establish Special Education Program**

(1) All handicapped children in Montana are entitled to a free, appropriate public education provided in the least restrictive alternative setting. To the maximum extent appropriate, handicapped children, including children in public or private institutions or other care facilities, shall be educated with children who are not handicapped. Separate schooling or other removal of handicapped children from the regular educational environment may occur only when the nature or severity of the handicap is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.

(2) After September 1, 1977, the board of trustees of every school district must provide or establish and maintain a special education program for every handicapped persons as herein defined between the ages of 6 and 18, inclusive.

(3) On or before September 1, 1990, the board of trustees of each elementary district shall provide or establish and maintain a special education program for each handicapped preschool child between the ages of three and six, inclusive.

(4) The board of trustees of any school district may meet its obligation to serve handicapped persons by establishing its own special education program, by establishing a cooperative special education program, or by participating in a regional services program.

*** 20-7-402. Special Education to Comply with Board Policies.**

(1) The conduct of special education programs shall comply with the policies recommended by the Superintendent of Public Instruction and adopted by the Board of Public Education. These policies shall assure and include but are not limited to:

- (a) placement of handicapped children in the least restrictive alternative setting;
- (b) due process for all handicapped children, including the appointment of a surrogate parent if necessary;
- (c) use of child study teams to identify handicapped children and use of instructional teams to plan individual education programs;
- (d) comprehensive evaluation for each handicapped child; and
- (e) other policies needed to assure a free and appropriate public education.

Most students with severe disabilities continue to be segregated from other students in public schools and States continue to rely far too heavily on separate "state Schools" and educational settings in hospitals and other segregated institutions.

The Education of the Handicapped Act State Grant Program (EHA-B) (PL 94-142) as amended, is a basic state grant program which allows states to cover part of the cost of providing special education and related services to handicapped children ages 3-21. The primary purpose of this program is to assist states in providing a "free appropriate public education" in the least restrictive setting.

There were 14,755 children with handicaps served under the EHA-B program in Montana during the 1986-1987 school year.

There is all-too-plentiful research evidence that educating students with special needs in the regular classroom is far more beneficial than using segregated environments (Lipsky & Gartner, 1989; Wang, Reynolds, & Walberg, 1988).

While the number of children with disabilities served under The Education of the Handicapped Act State Grant Program (EHA-B) and Chapter 1 Handicapped Programs of the Education and Consolidation Improvement Act - State Operated Programs (ECIA (SOP)) has seen a 19% increase during the past 11 school years, many of these students are not receiving educational services in integrated settings with all other children. During the 1985-1986 school year, only 26% of the students received the majority of their educational services in the regular classroom (U.S. Department of Education, 1988).

Montana served 59% of children with disabilities in the regular classroom during the 1986 school year. However, only 15% of those served in this most integrated setting were children with severe disabilities. Table 3 illustrates the different educational environments in which children with disabilities in Montana received their education.

As shown in Figure 19, most education consumers surveyed in Montana during 1988 reported that they received most of their education in special classes in regular school.

Nationally, a small number of handicapping condition categories account for a high percentage of students in fully integrated regular class settings. More segregation may exist for other handicapping condition categories, such as mental retardation, multiple handicaps, and deafness and blindness.

For example, during the 1985-1986 school year, the speech or language impaired handicapping condition category served 66% of its population in the regular class setting. However, only 3% of those with mental impairments, 4% of those with multiple handicapping conditions, and 7% of those with deafness and blindness were served in the regular class setting (U.S. Dept. of Education, 1988).

Chapter 1 Handicapped Programs of the Education and Consolidation Improvement Act - State Operated Programs (ECIA-SOP) PL 89-313 as amended, provides support for handicapped children and youth (ages 0-20) in state operated and supported programs, such as hospitals or facilities for children with blindness, deafness, mental retardation, or emotional disturbances. Educational programs may also be provided in community-based day care program centers, or may provide assistance for homebound children under state care. Children who previously participated in such a program and are now being educated by a local educational agency are eligible for services funded through the ECIA (SOP) program through that local school system.

As shown in Table 4, 614 children with disabilities were served under the ECIA (SOP) program in Montana during the 1986-1987 school year.

*** Not all states provide education and related services to the entire range of eligible children.**

As of the 1986-1987 school year, only 21 states provided special education and related services across the full 3-21 age range defined in P.L. 94-142. (U.S. Department of Education, 1988)

All school districts and special education cooperatives provide identification, location and evaluation services for handicapped children ages 0-21. Services to handicapped children ages 0-5 are permissive in those school districts or special education cooperatives which provide preschool services. The following special education and related services may be provided for handicapped children: home-based and/or school-based programs including transportation, occupational therapy, physical therapy, speech/language programs and parent training.

A variety of agencies operate preschool programs. School districts, special education cooperatives, Head Start and social rehabilitative services agencies. Contracted organizations are among those offering preschool programs. On or before September 1, 1990, the board of trustees of each elementary district shall provide or establish and

maintain a special education program for each handicapped preschool child between the ages of 3 and 6, inclusive. Services to handicapped pupils in the 6-18 age group are mandated. All school districts and special education cooperatives may provide such special education and related services as:

- (i) Resource room instruction
- (ii) Self-contained classroom
- (iii) Transportation
- (iv) Parent counseling and training
- (v) Speech/language programs
- (vi) Occupational therapy
- (vii) Physical therapy
- (viii) Out of district placement, and
- (ix) Homebound programs

Special education and related services for the 19-21 age group are permissive. Services available to the 19-21 age group, if a district and special education cooperative elect to serve this age group, may include:

- (i) Resource room instruction
- (ii) Self-contained classroom
- (iii) Transportation
- (iv) Parent counseling and training
- (v) Speech/language programs
- (vi) Occupational therapy
- (vii) Physical therapy
- (viii) Out of district placement, and
- (ix) Homebound programs

* Many students with disabilities are not receiving the support they need to be placed in integrated settings because states tend to interpret federally-defined "related services" so literally that if a service needed is not included in the "letter of the law," it is not provided.

Obtaining necessary related services and educational supports is often extremely difficult. Services are often provided according to what is available in the local districts, rather than according to which services are actually needed (Documents prepared by the

Consortium for Citizens with Disabilities' Education Task Force on the Reauthorization of the Education of the Handicapped Act, 1989).

Consumers surveyed in Montana report that in circumstances where related services such as preschool services, after school tutors, and related services were not provided to them because the services available were not appropriate for their needs, or were simply not available. Related services, as defined in P.L. 94-142, are transportation and such developmental, corrective, and other supportive services as are required to assist a child with disabilities to benefit from special education. However, since twelve different related services categories are pre-defined at the federal level, assumptions are often made at the state level that these are the only related services that may need to be made available to an individual receiving special education services. Some states have legislated related services requirements that are not specifically mentioned in the federal law for services such as mobility training, summer school programs, and materials (Esterson & Bluth, 1987).

* Available special education data is problematic, and much needed information is unavailable. Attempting to determine the number of individuals with developmental disabilities included in education statistics is very difficult. Thus, issues such as placement of children with the most severe disabilities are difficult to determine and analyze.

Several factors contribute to the problematic nature of current special education data. First, while federal language exists with reference to the definitions of each of the handicapping condition categories, states exercise a significant amount of discretion in defining the "state level contents" of these categories. Thus, the ability to evenly compare data across handicapping condition categories, for example, is greatly hindered.

It is very difficult to determine the number of individuals with developmental disabilities included among the statistics. This difficulty highlights the need for each state to assess how its special education criteria are used to assess the population of those with developmental disabilities.

State submission to the Department of Education of some important data is voluntary. For example, data on related services for the 1986-1987 school year were not required, thus, only a handful of states provided it. If collected by individual states, data may be available from the state education agency. Because related services data are not required by the U.S. Department of Education, data on definitions and utilization for individual states are available only at the state level.

Education data for different topic areas is not consistently available for the same school year. Thus, the ability to supplement data of different focus areas is hindered.

*** An alarmingly high percentage of special education students are dropping out and thus are less well educated than their non-disabled peers.**

Americans with disabilities have far less education, as a group, than do Americans without disabilities. Forty percent of all people with disabilities did not finish high school. This proportion is nearly three times higher than in the non-disabled population, where only 15% of adults have less than a high school education (Louis Harris and Associates, Inc., 1986)

Twenty-six percent of the students in special education dropped-out in the 1985-1986 school year, 10% higher than even the highest regular education drop-out estimate, and the percentages for the handicapping conditions associated with developmental disabilities account for over half of this total percentage (U.S. Department of Education, 1988).

Nationally, the drop-out percentages for many of the handicapping condition categories which are most likely to include those with developmental disabilities are significant. For example, those with other health impairments comprised 31% of the total percentage of students 16 years and older who exited the educational system by dropping out during the 1985-1986 school year, those with mental impairments comprised 24%, and those with multiple impairments comprised 18%. (U.S. Department of Education, 1988)

In Montana for the 1985-1986 school year, the drop-out rate for students with handicaps was 20%, significantly lower than the national average discussed above.

Estimates of the percentage of "regular education" student drop-outs varies. The U.S. Center for Education Statistics estimates 14%, of the U.S. Bureau of the Census estimates 16%, and the U.S. Department of Labor estimates 18%. Clearly, the drop-out issue is a problem for both regular and special education.

*** Students are "falling through the cracks" because adequate mechanisms do not exist to follow and to link them to the transitional services they need.**

Swelling the ranks of the unemployed with disabilities are youths recently transitioned from high school programs into the competitive workplace without marketable skills.

Since 1979, more than 2.5 million youths with disabilities have graduated from the public school system in our country. Of that number, only 23% are competitively employed or in post-secondary training. Students with mental retardation and learning disabilities typically represent between 50-69% of the population designated as handicapped in public schools (Project PERT, 1985). The concept of learning disabilities applied to issues of vocational needs and supported employment is relatively new. Studies done in states like Arizona and Pennsylvania (Project PERT, 1985) suggest that between 45-60% of adults with learning disabilities were unemployed and needing rehabilitation services.

A study conducted during the month of September 1988 by the Montana University Affiliated Program Satellite conducted found that of the 237 students with learning disabilities, nearly 21% were reported to be in supported employment situations. An additional 38% were appropriate for but not placed in employment situations. Thus, 59% are either in or appropriate for supported employment activities. Forty-one percent of the surveyed group were viewed as not appropriate for supported employment by those responding to the survey. Of the 52 students with mental retardation surveyed, 75% were in supported employment situations. An additional 10% were appropriate for but not

placed in employment situations. Thus, 85% are either in or appropriate for supported employment activities. Fifteen percent were viewed as not appropriate for supported employment (Offner, Arnold, Wittekiend, 1988). For further details see the section on Employment.

Annually, the Montana State Office of Public Instruction tabulates the number of handicapped students by age and handicapping condition for federal reporting purposes. As of December 1, 1987, there were 1,421 students with learning disabilities 16 years of age and older receiving services. There were 299 students with mental retardation in this same age range receiving services. Using the percentages derived from the September MSSED Telephone Survey, 59% of the LD group (838) and 85% of the MR group (254) are appropriate for employment related activities and experiences. However, in the LD group only 21% (298) could be expected to be placed in actual supported employment. For the MR group, 75% of the 299 (224) could be expected to be placed in actual supported employment. This information is presented in the Table 34.

*** There is increasing demand for child care and pre-school services for the growing numbers of working mothers in all income groups.**

Research indicates that early childhood services for children with disabilities and children at risk of disabilities appear to enhance intelligence in some children; produce substantial gains in motor development, language, emotional stability, cognitive abilities and self-help skills; prevent the development of secondary handicapping conditions; reduce family stress; increase family income potential; reduce societal dependency and institutionalization; reduce by up to 50% the need for special class placement at school age; and be cost beneficial by as much as 236%. (Weintraub and Ballard, 1986)

Along with state efforts to fund child care, the number of states which fund pre-kindergarten programs has greatly increased "nearly quadrupling in the past decade" (Mitchell, 1989, p. 666.) By 1989, 62% of the states had appropriated funds for state-initiated pre-kindergarten programs and/or direct contributions to Head Start programs.

The Education of the Handicapped Act Amendments of 1986 established the Preschool Grants Program. A federal level goal of the program is to serve all 3-5 year old children with handicaps no later than fiscal year 1991. To help states meet this goal, increased financial incentives were established. Under the program, states are eligible for a two-part grant.

As of publication of the Tenth Annual Report to Congress on the Implementation of the Education of the Handicapped Act (U.S. Department of Education, 1988), twenty-two states, as well as the Virgin Islands, currently mandate the provision of a free appropriate public education to all handicapped children from 3 years of age. The mandate in six of these states, Guam and Puerto Rico extends to birth.

The current mandate in Montana is to provide services beginning at the age of six. As mentioned before, beginning in September, 1990, the mandate will extend services to children aged 3 - 6 as well. Montana's child count for 1987-1988 indicated that 1420 children aged 3 - 5 with handicaps received preschool services. According to Office of Public Instruction estimates, an additional 108 children needing such services are not receiving them.

For school year 1987-1988, all states elected to participate in the Preschool Grants Program. For the 1987-1988 school year, states estimated that an additional 30,665 children would be served, an increase of 11% over the previous year. Fifty states and territories estimated an increase, with increases ranging from 9 to 6,500 children. the remaining nine states and territories did not estimate increases for school year 1987-1988 (U.S. Department of Education, 1988).

The Head Start program provides comprehensive developmental services to improve the quality of life for children and their families. Intended primarily for preschool children from low income families, the program seeks to foster the development of children and enable them to deal more effectively with both their present environment and later responsibilities in school and community life. Head Start programs emphasize education; social services; medical, dental, nutrition and mental health services; and parental

involvement to enable each child to develop and function at his or her highest potential. The Head Start Act also requires that no less than 10% of the total number of enrollment opportunities in Head Start programs in each state be available for handicapped children, and that services be provided to meet their special needs.

Head Start is currently serving only approximately one out of every six of the eligible low-income preschool children (U.S. Department of Health and Human Service, 1988).

While the Head Start Act requires that no less than 10% of the total number of enrollment opportunities in Head Start programs in each state be available for children with disabilities, there is no responsibility within the state for overseeing this requirement (Community Services Act, 1974).

* There is a serious shortage of qualified special education and related services professionals.

Projections of both student and professional demographic data indicate that over the coming years the shortages will reach crisis proportions and seriously impede the ability to provide students with disabilities the special education and related services they are guaranteed under Federal Law.

States reported that, for the 1985-1986 school year, an additional 27,474 special education teachers were needed to fill vacancies, and that 13,712 staff other than special education teachers were also needed. (U.S. Department of Education, 1988)

The demand for personnel trained to serve the 14,745 students with special needs in Montana is dramatic. The Office of Public Instruction reports that a current shortage of 55 teachers with cross-categorical preparation exists and that at least ten school districts in Montana are unable to hire a certified special educator. In addition, 25 special educators in Montana are teaching with partial (emergency) certification due to the extreme need (Office of Public Instruction, 1989). Consistent with national prevalence data, the majority of Montana's students with handicaps receive their education in regular

classes on a full-time or part-time basis (about 75%). The majority of students receiving special education services in Montana are classified as learning disabled (54%). According to a study on state variation in placement of children with handicaps in segregated environments (Danielson & Bellamy, 1988), the state of Montana ranks sixth in the nation with respect to the percent of students who are receiving special education and related services in regular classes. Increasing numbers of students with moderate and severe handicaps also are being placed in regular classes in Montana. This trend is expected to continue, given Montana's strong commitment to the intent of Public Law 94-142 and placement in the least restrictive environment.

The need for special education personnel in Montana must be seen in terms of quality as well as quantity. As more students receive educational services in regular classes, special educators work in collaboration with regular educators to plan, implement, and evaluate programs. Because Montana is a rural state, persons serving students with disabilities often function in various capacities. Competencies such as collaborative consultation skills, pre-referral intervention strategies, knowledge of various generic instructional approaches, knowledge of computer-assisted instruction, instructional area skills (e.g., expertise in reading or math), and classroom organization skills to accommodate diversity are among those needed for successful educational service delivery (Stainback & Stainback, 1989). A solid background in regular education is needed to provide the foundation for building expertise in these competency areas. Advanced training is necessary for teachers to gain the needed expertise for working in more consultative capacities (Putnam, 1989).

*** State discretion excludes many children with disabilities from special education and related services.**

While federal law and regulation refer to eligibility of children with disabilities ages 3-21 for special education and related services under Part B of The Education of the Handicapped Act, states exercise a significant amount of discretion in setting state level

upper and lower age limits for these services. Thus, it is often the case that individuals with developmental disabilities do not begin to receive educational services at the age of three, nor do all individuals with developmental disabilities receive educational services until the age of 21.

The 3-21 age range for service eligibility stated in federal law and regulation is not being implemented across all states and territories. Only approximately 42% of the states provide services for eligible students in the 3-21 age range as of school year 1986-1987. (U.S. Department of Education, 1988. The author calculated the percentage based on their data. This is not a statement from their text.)

As mentioned previously, Montana mandates special education and related services to children within the 6 - 18 age range, with services to children outside of that range being available at the discretion of the school districts. Beginning September 1990, however, Montana services for children aged 3-6 inclusive will be mandated.

*** Despite the importance of parental involvement, many parents are not attending IEP conferences or becoming involved in the educational planning process (The Robert Wood Johnson Foundation, 1988).**

After a five-year RWJ study of five school systems, it was found that, while P.L. 94-142 intended that the development of a child's Individualized Education Program (IEP) involve parents, usually fewer than half actually attended their child's IEP meeting.

*** Funding for special education programs is woefully inadequate.**

Federal funding contributions for P.L. 94-142 fall far below the statutory maximums. The initial commitment of the federal government was to reimburse the state governments and local districts for 40% of the national average per pupil expenditure (NAPPE) by 1982. Instead, the total actual appropriation for P.L. 94-142 as a percentage of the NAPPE in relation to the number of children being served has never exceeded 12% during the late 1970's. It reached a low of 7% in the early 1980's. As a result of continuing

Congressional commitment to the program, funding has increased to a slightly better level of 9% (Consortium for Citizens with Disabilities, 1989).

As shown in Figure 20, Montana EHA-B grant awards have increased by 633% from 1977 to 1988.

* While a new entitlement for infants and toddlers has been authorized by the Handicapped Infants and Toddlers Program, Part H of the amendments to the Education of the Handicapped Act of 1986, there are disincentives to implementation.

The Handicapped Infants and Toddlers Program provides financial assistance to states for the provision of early intervention services to children with disabilities from birth through two years of age.

The U.S. Department of Education, in response to a letter from the Pennsylvania Early Intervention Interagency Coordinating Council, has officially acknowledged that, starting October 1991, infants and toddlers with developmental delays will have a right to early intervention services under Part H of P.L. 99-457. This has important implications, because confirmation that all eligible children and families will be entitled to services could lead states to limit the scope of their infant-toddler programs, based on potential cost (Mental Health Law Project, April 7, 1989).

Although states have some discretion regarding the range of services which will be available, minimal criteria are specified, and these criteria must be met in a state's service delivery system. Funding authorizations for the Handicapped Infants and Toddlers program and the Preschool program were based on federal estimates of the number of children to be served under these two programs. Both estimates are considered far too low. It was estimated that the number of 0-2 year-old children in need of early intervention services would be approximately 320,000. However, estimates developed by the first 15 states who indicated they would apply for Part H grants show the number of eligible infants and toddlers would be closer to 526,000. It was also estimated that

approximately 333,000 3-5 year-old children would need services, of which approximately 70,000 are presently unserved (Smith, 1988).

NADDC RECOMMENDATIONS

1. The use of segregated school facilities should be eliminated.
2. The 0-21 age range for service eligibility should be implemented across all states and territories. Eliminating the opportunity for states to exercise discretion with regard to the age range will help to ensure that more individuals with developmental disabilities receive early intervention, pre-school, as well as vocational services.
3. The least restrictive environment (LRE) (most enabling) concept must be scrupulously adhered to. The individual should not have to change before he or she can take part in the most integrated setting, but rather there should be more emphases on changing the related services so that he or she can take part in this setting. Federal language should help clarify that "whatever it takes" are the services that should be delivered.
4. A plan should be developed for better federal level data collection. Federal requirements should help insure that all data that is presently collected continues to be so, that other areas of data collection are added as needed, that comparable information is readily available for the same school year, and that data is made comparable by mandating consistency across the use of various definitions.
5. Federal policy should help ensure that each Local Education Agency (LEA) has an on-going drop-out prevention program which specifically addresses the needs of the special education population.
6. Plans for transition should be developed and implemented at the local levels. Mandatory collection and reporting of appropriate data may help to ensure that more individuals receive such services.

7. Adequate federal funds should be available in order to support and enhance state and local contributions. Federal contributions should move quickly towards the originally promised 40% reimbursement rate.
8. Educational services systems should be designed around individual needs. The focus should be on preparing individuals for life, giving them the functional knowledge and skills to actively take part in it. Functional curriculums should be developed and adopted by local education agencies (LEAs).
9. Public awareness should be heightened regarding the need for appropriate expectations of individuals with disabilities, since only behaviors that are expected can be achieved.

MONTANA RECOMMENDATIONS

The primary source for Montana's recommendations is the Temple University Consumer Survey conducted by our state in 1989. Recommendations derived from the survey are followed by parenthetical reference to specific item numbers in the survey, indicating the percent of respondents dissatisfied with a particular service and the total number of respondents to that particular item. If the issue also arose during the public forums, that source is noted in the parenthetical reference as well.

1. Provision of early intervention and preschool services for children with disabilities must be expanded and individualized to appropriately meet children's needs (Items 3.1: 28.5% of 21; 3.2: 18.8% of 16).
2. Special classes in regular schools need to be qualitatively improved, providing services more appropriately individualized, suited to the needs of children with disabilities (Item 3.5: 27.5% of 29).
3. Opportunities for children with disabilities to participate in summer school programs must be expanded through increased funding for such activities (Item 3.11: 30% of 10).

4. Physical therapy, occupational therapy, and communication services for children and adults need to be increased and individualized to meet their unique needs (Item 6.6: 20.5% of 34; 6.7: 24.9% of 28; 6.8: 16.6% of 42).
5. Need for an increased training in use of transportation systems needs to be emphasized for older children and adults with disabilities (Item 7.6: 37% of 8).
6. There is a need in Montana for a formal system of transition services to insure that students graduating from special education programs can receive adult services within their local communities.
7. The system of higher education in Montana and its human service system need to establish a mechanism for improved communication and goal-setting regarding training needs for teachers and direct-service providers. Specific training for those regular classroom teachers participating in mainstreaming programs needs improvement.
8. Adult education for persons with disabilities who require continued instruction in academics should be established.
9. Support services for families of children with disabilities, including counseling, group therapy and communication strategies, need to be instituted or expanded.
10. Family-focused programs need to be more closely aligned with existing school services. Specific features could include: peer or sibling tutoring, respite training for neighbors or friends, summer education and recreation programs.
11. Children with severe behavior and emotional problems in Montana are underserved. This particular group of children with disabilities require increased services in both school and family settings.
12. Refinement is needed in the comprehensive and coordinated child findd program to insure that handicapped infants and toddlers in the birth through 2 age group are identified early and referred to appropriate service providers. Efforts should also include coordinated transition plans for 0 - 2 children's movement from

developmental disabilities services to preschool programs for 3 - 5 year preschool programs (OPI State Plan, 1989).

13. Preschool aged children with handicaps should be mandated to receive public school services. Beginning in September 1990 such children in Montana will be entitled to a free and appropriate public education (OPI State Plan, 1989).
14. There is a strong need to address employment programs and training opportunities for the learning disabled population as they transition from high school into the work world. Under the current system it is difficult to obtain services for these individuals after they leave school. The educational program for students with learning disabilities typically focuses on academic assistance with very little emphasis on supported employment and preparation for the world of work. As a consequence, many of our learning disabled students are not employed after high school.

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APPENDIX D

FIGURES AND TABLES

EHA-B and ECIA (SOP), Number of Children 3-21 Years Old
Served in Different Educational Environments
During School Year 1985-1986, by
Educational Environment Category
ALL CONDITIONS

<u>CATEGORY</u>	<u>NUMBER</u>
Regular Classes	9,137
Resource Room	2,924
Separate Classes	2,729
Public Separate Facility	120
Private Separate Facility	0
Public Residential Facility	197
Private Residential Facility	8
Correctional Facility	65
Homebound Hospital Environment	230

TABLE 3

MOST EDUCATION RECEIVED

CHILD RESPONSE



ADULT RESPONSE

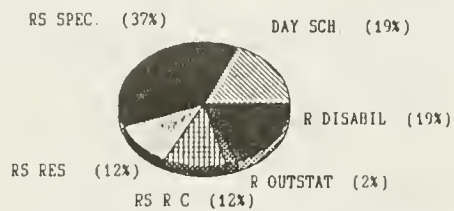


FIGURE 19

Consumer Survey 1989

RS = Regular School Special Class
 RS RES = Regular School Resource Room
 RS RC = Regular School Regular Class
 DAY SCH. = Special School (Day)
 R OUTSTAT = Special residential School Out-of-State
 R DISABIL = Residential Facility for
 Persons with disabilities

	EHA-B	ECIA	BOTH
All Conditions	14,755	614	15,369
Learning Disabilities	7,532	4	7,536
Speech Impaired	4,591	36	4,627
Mentally Retarded	1,195	133	1,328
Emotionally Disturbed	634	42	676
Hard of Hearing & Deaf	162	111	273
Multi-Handicapped	276	100	376
Orthopedically Impaired	125	24	149
Other Health Impaired	163	28	191
Visually Handicapped	62	122	184
Deaf-Blind	15	14	29

TABLE 4

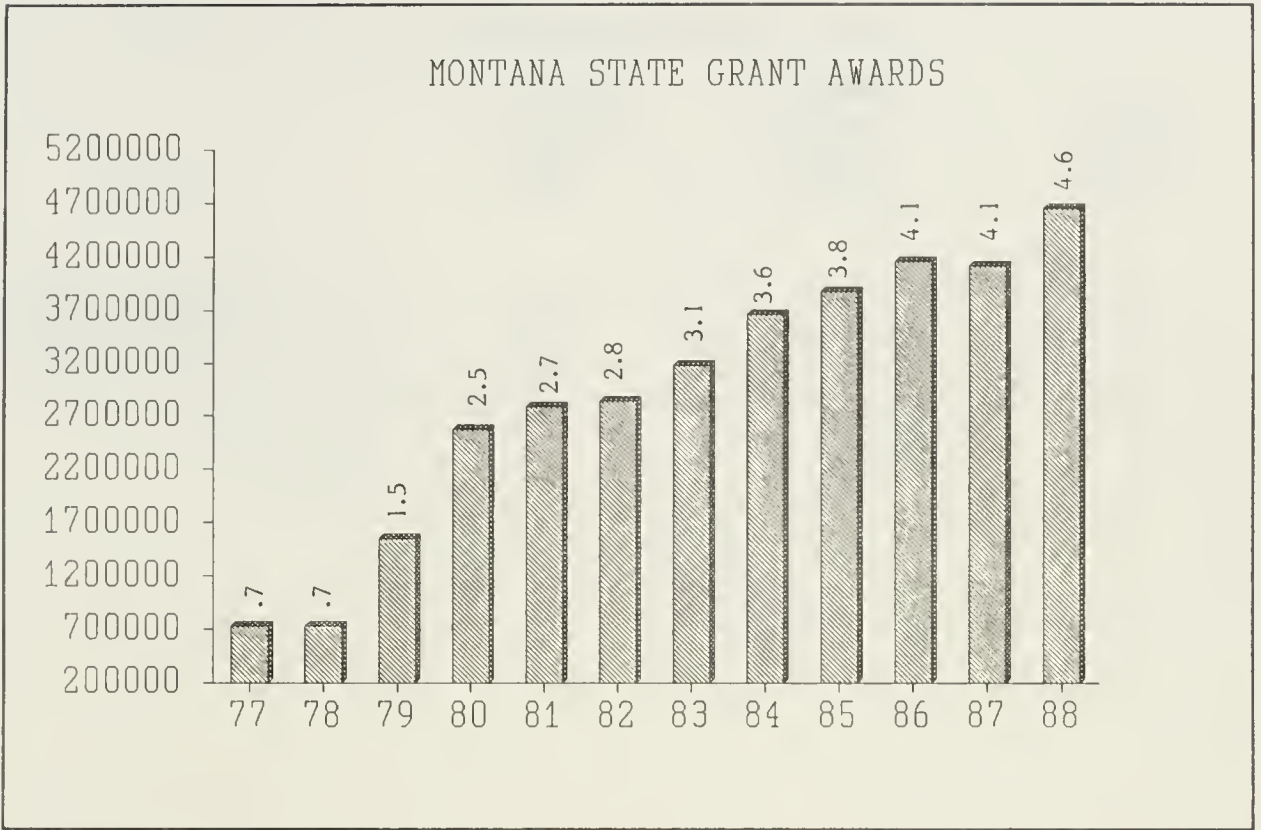


FIGURE 20
Awards under Federal EHA-B Program

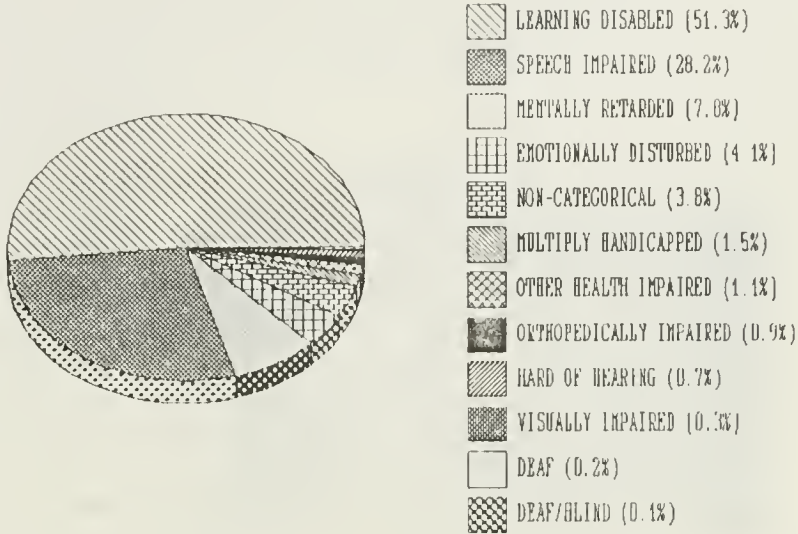
Level of Satisfaction with Services - Education

<u>Service</u>	<u>Percentage of Participants Receiving Services</u>	<u>% Satisfied of those Receiving Services</u>	<u>% Dissat. of those Receiving Services</u>
<u>Educational Services</u>			
Early Intervention	23%	74%	9%
Special Class in Regular School	32%	58%	32%
Related Services	1%	100%	-
Summer School	11%	73%	18%

PERCENTAGES OF HANDICAPPING CONDITIONS AGES 3 - 21

MONTANA SPECIAL EDUCATION ENROLLMENT 1988-89

Total Enrollment = 14,784



NUMBER OF STUDENTS ENROLLED IN SPECIAL EDUCATION IN MONTANA

WITHIN REPORTED CATEGORIES (TOTAL ENROLLMENT = 14,784)

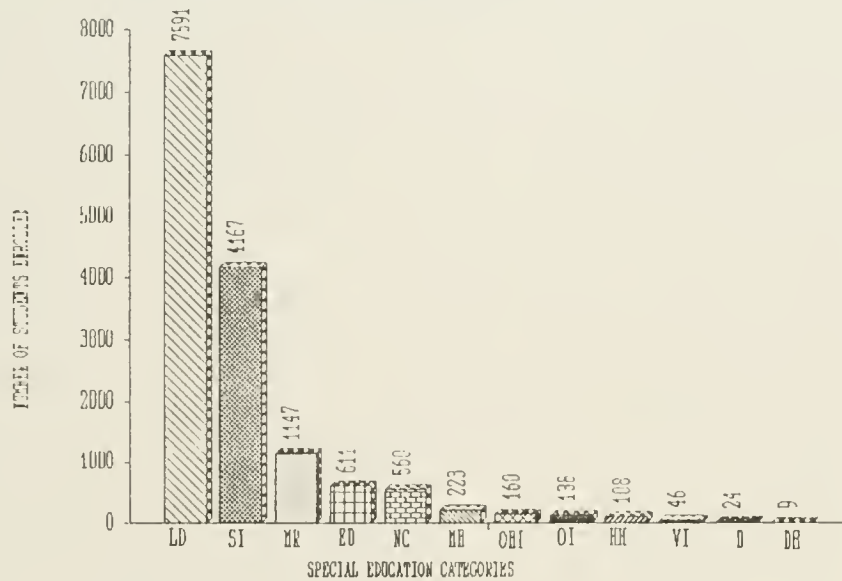


FIGURE 21

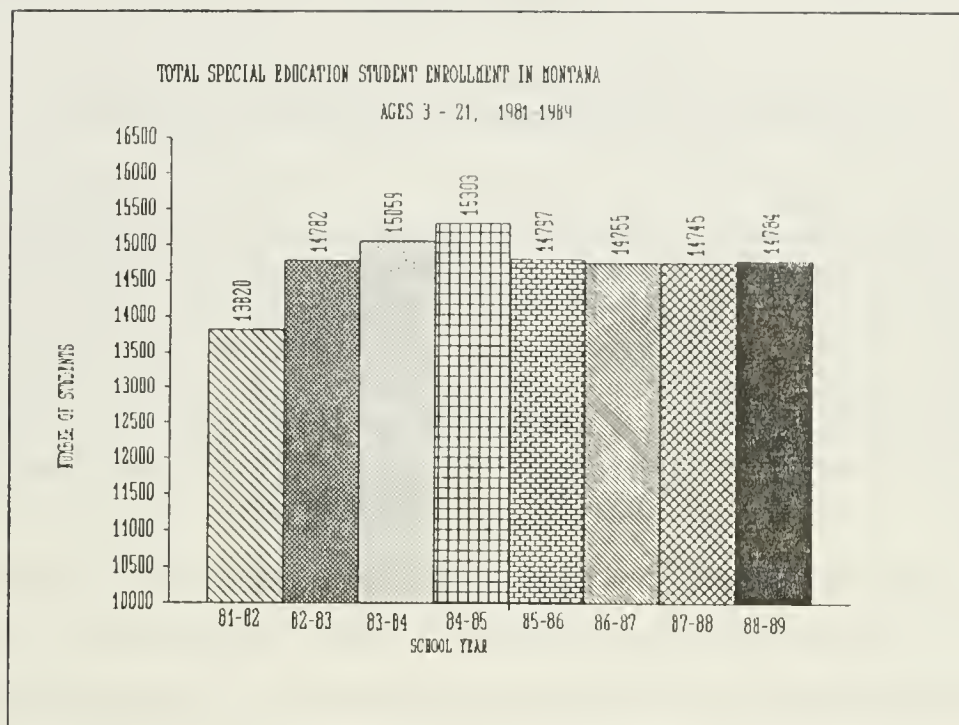


FIGURE 22

EMPLOYMENT

A VISION OF EMPLOYMENT FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

It is in the area of work, even more than social life and activities, that disability excludes people most from the mainstream of American life. For most Americans, striving to reach one's abilities amounts to working to achieve career and financial goals. Our society expects people to work, and the preeminent criterion by which a person is judged and measured is the job that he or she does. Americans below retirement age, who do not work, live somewhat apart from the mainstream of life in this country. Unemployment excludes them from many of the common experiences known by most Americans. (Taylor et al., 1987)

Therefore, all Americans who want to work, regardless of disability, should be employed at a liveable wage. People should have a right and be able to choose and change their employment. As technology and new skills are applied to their jobs, resulting in increased productivity, employee income should increase. Workers should advance to higher paying and higher status jobs throughout their careers. Pay for jobs should be based upon the status of the job in society and the productivity of the person doing the job and not on race, creed, sex, age, or disability of the employee. Individuals should not be discriminated against in hiring nor should they be exploited by unscrupulous employers. Employment should be as stable as the individual wants it to be.

Employees should receive adequate wages and benefits including: health, unemployment compensation, workers and disability compensation, pension, vacation, and sick and compassionate leave. People should receive the necessary education, training, and retraining needed to become and remain employed. There should be effective means for linking people in search of jobs with job openings.

The public sector must act as a buffer to the private sector by providing unemployment compensation and public service jobs when unemployment becomes problematic. Employers should increasingly accept their corporate responsibility for the

welfare of their employees. People should increasingly view work as an integral part of their life about which they can take pride.

The vision for people with developmental disabilities is essentially the same as it is for anyone else in society. All people should contribute to society in some way. Society tends to view non-contributing members with hostility, charity, or perhaps pity. The member of society who is precluded from participation understands that he or she is held in low-esteem. Our challenge is to find something that each person can do to be productive. Productive activity opens doors to social acceptance, companionship, and important informal community networks.

People with developmental disabilities will require special assistance (supports) if they are to participate in the economic activities of our society. These supports are wide-ranging depending upon the special needs of individual and the special requirements of the job. For some individuals these supports may be minimal, but for others they will be extensive. These supports are not unlike those required by workers without disabilities. Special tools are often required for workers to do particular jobs. Science and technology can play a major role in creating a work environment in which a person with developmental disabilities can succeed, but even more important will be the positive and supportive relationships that the person develops with co-workers and supervisors. Examples of supports include: communication devices, the ability of co-workers to communicate in sign language, a special wheelchair and or ramps, more intensive supervision, special transportation assistance, specially designed tools, job design and engineering, a personal care attendant, flexible hours, job sharing, and specialized assistance in locating job opportunities.

Services that prepare the individual for and maintain the individual in employment also vary with the individual and the type of employment he or she is seeking or already doing. The skills and capabilities may be quite different from job to job, but some are general (e.g., basic social and problem-solving skills, responsiveness to direction and supervision, communication skills).

Our vision calls for the best use of science and technology being brought to these areas as well. Examples of services include: specialized on-the-job and off-the-job training; physical, occupational, speech, and language therapy; vocational and psychological counseling; prescription drug therapy; other medical treatment; general and vocational education; and vocational and technical training. These supports have associated costs that may be prohibitive for some employers; therefore, there may be a need to provide additional compensation to employers for providing these supports. There are a variety of methods that might be employed to compensate the employer: tax credits and other tax incentives, sub-standard wage allowances with a subsidy going to the employee, a direct subsidy to the employer, the purchase or direct provision of certain supports to individuals by the public and voluntary sectors, and accelerated depreciation. These individual employee and employer supports are needed by people with development disabilities and by other groups as well. For some individuals, special supports need to be provided for relatively short periods of time, but others may require ongoing support over their whole careers.

All people, regardless of the severity of their disability, have both the right and the responsibility to be productive. Individuals have the right to choose how they will be productive whether through employment, contributing to their household, or contributing to their community. Each of these avenues has its own rewards. The means of achieving this societal goal are specialized preparation of each individual and the provision of individualized supports.

BARRIERS TO THE VISION OF EMPLOYMENT FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

Social/Economic/Demographic Trends and Barriers

- * **People with developmental disabilities want to work but are not working.**

From the perspective of people with disabilities, only 33% of the respondents in the Harris Poll (Taylor et al., 1987) reported some employment. Of the 66% of respondents not working, two-thirds of them wanted to work. The conclusions of the Harris Poll are

obvious: there are employers willing to hire people with disabilities who want to work. These data are confirmed by the Survey of Income and Program Participation (1984) which indicates that 42.5 percent of people between the ages of 18 and 64 with a work disability (people who reported that the disability prevented them from working or limited the amount or type of work they could do) are employed. At the same point, according to the National Health Inventory Survey (1985), 71.3% of the general population in the same age group were employed (Griss, 1988). In 1978, 41.1% of those with work disabilities were employed (Vachon, 1987). Six years later, in 1984, only 42.5% were employed. During the same six-year period, there was over a 9% growth in jobs (Bureau of Labor Statistics, 1984) that more than offsets the 3% growth in employment by people with disabilities.

"The majority of those not working and out of the labor force must depend on insurance payments of government benefits for support. Eighty-two percent of people with disabilities would give up their government benefits in favor of a full-time job" (Harkin, 1989).

Data from the 1988 Needs Assessment of Montanans with Disabilities identified 649 clients who were determined by their primary service provider as appropriate for supported employment. It is interesting to note that, although this study will serve as a baseline from which to measure future gains for supported employment in Montana, supported employment has increased by 134% over the past two years.

Over half of the study's sample (67%) is comprised of people with mental retardation. The next largest group is people who have some form of mental illness (20%). Other disability groups represented are: brain injury (4%), learning disability (2%), physical disability (2%), sensory impairment (1%), and cerebral palsy (1%). Males dominated the sample at 57%. Average age of the clients considered appropriate for supported employment is 32. Eighty-two percent of the sample is 40 or younger, and half of that group (41%) is between 21 through 30 years old (Table 6).

Thirty-nine percent of the clients appropriate for supported employment are in supported employment positions. Supported employment typically is in one of five jobs: janitor (34%), food service (16%), dishwashing (10%), landscaping/yard work (8%), and maid (6%) (Offner, Arnold, Wittekiend, 1988).

*** Employers are willing and able to hire people with developmental disabilities.**

Employers are willing to hire workers with disabilities, but there are some barriers to be overcome. According to the Harris Poll of employers, "Overwhelming majorities of managers give disabled employees a good or excellent rating on their overall job performance. Only one in twenty managers say that disabled employees' job performance is only fair, and virtually no one says that they do poor work" (Taylor et al., 1987). Seventy-seven percent of employers rate employees with disabilities as more productive or as productive as non-disabled employees. Seventy-nine percent of these managers report that people with disabilities work as hard or harder than their peers with no disabilities. The majority of managers say that their companies can provide in-house training for disabled employees. Private programs exist to assist employers with job accommodation strategies (e.g., Job Accommodation Network [JAN] [1-800-526-7234]), demonstrating private sector willingness to hire people with disabilities. Companies that have not hired workers with disabilities in the last three years indicate that a lack of qualified applicants is the most important reason (66%). Only 37% of the companies surveyed have established policies or programs for hiring people with disabilities.

The following quotation from Mike Quinlan, president of McDonalds, illustrates the potential for business, itself, taking a leadership role in hiring people with severe disabilities: "Many people who had once been considered 'unemployable' by other employers now hold jobs of real responsibility within the McDonald's system. Their outstanding performance has disproved the myth that hiring the disabled worker is unprofitable. McDonald's disabled employees have proven themselves to be exceptionally hard workers. They are dedicated, loyal employees with low absentee and turnover rates.

They are driven by a desire to prove themselves as contributing members of our society. And their persistence has served as a model for our crews and staffs alike. The McJobs program has helped turn sad stories into success stories. And we're proud of each and every one of them" (McDonalds Corporation, "McJobs Is Disabling a Myth about the Disabled," cited in Hopkins et al., 1988, p. 117).

There have been numerous successful efforts by the private sector to employ people with severe disabilities. The Job Accommodation Network (JAN) is a national information network and consulting service for employers that are considering employing people with disabilities. Organized labor is involved. The AFL-CIO, International Association of Machinists, and American Federation of State, County, and Municipal Employees have programs that focus on hiring and retaining people with disabilities. All across the country employers and employees with disabilities are daily proving that people with disabilities can contribute to their own welfare and to the economic productivity of the country.

Many employers, on their own or with minimal encouragement from the public sector, have hired people with severe disabilities. IBM has conducted computer programmer training courses for people with severe disabilities since 1972. Marriott Corporation trains small groups of workers with mental disabilities to perform jobs in the company cafeteria and after training hire them or refer them for placement with another company. Woodward & Lothrop has hired more than 100 workers with mental retardation since becoming involved with an Association of Retarded Citizens program twelve years ago. McDonalds uses its own managers in a supported employment program called "McJobs." "The program, operating in 24 regions and 44 stores, boasts more than 3,000 graduates so far" (Hopkins et al., 1988).

Supported Employment for Montanans with Disabilities

A Needs Assessment for Montanans with disabilities discussed previously in 1988, looked at various life aspects of people with disabilities by using a mail-based survey for two different populations. One group consisted of a random sample of people in the

Department of Vocational Rehabilitation's caseload database. These could be people currently in a vocational rehabilitation program, people who have not yet received vocational rehabilitation, or people who successfully completed a vocational rehabilitation program. The other group consisted of people in community-based human service programs--like adult developmental disabilities programs, chemical treatment programs, and mental health day programs--who were not in a vocational rehabilitation program at the time of the survey.

Because not everyone is able to work a minimum of 20 hours, supported work was not limited in terms of minimum hours worked and therefore may include persons working as little as two hours per week. Supported employment was defined as: consumer-oriented, integrated, and nonsegregated employment based on an employee's informed choice, with appropriate ongoing services provided to the employee with a disability in order for the person to work productively in the community. This may include an individual placement, a mobile work crew, an enclave in industry, a transitional employment placement, community-based/semi-competitive employment, or community-based integrated employment (Offner, Arnold, Wittekiend, 1988).

*** The costs of supporting people with Developmental Disabilities in employment need not be prohibitive.**

Of people with work disabilities (disabilities that prevent or limit employment) between 18 and 64, only 15.3 percent report needing assistance with getting around, doing housework, meals, or personal care (Griss, 1988). The remainder are capable of carrying out these relatively complex tasks without assistance. These figures can be generalized to the workplace. Of those people needing assistance, the percentage of people needing assistance by conditions generally associated with developmental disabilities are presented below. This need for assistance can be projected to the employment situation.

<u>Diagnosis</u>	<u>Percent of Diagnostic Group Needing Assistance</u>	<u>Percent of Total Needing Assistance</u>
Back or spine problems	12.56	17.74
Blindness or vision problems	19.02	3.33
Deafness	0.00	0.00
Mental illness	17.42	2.59
Mental retardation	38.48	7.27
Missing appendages	25.04	1.43
Nervous or emotional problems	9.98	2.04
Paralysis	39.83	3.70

Senator Harkin addressed the question of workplace accommodation costs to employers. He cited a survey (A Study of Accommodations Provided to Handicapped Employees by Federal Contractors, Berkeley Planning Associates, June 1982) in which employers who were "obligated to provide 'reasonable accommodations' found that compliance was 'no big deal'" (Harkin, 1989). He also speaks of a 1987 Honeywell report that concluded, "the majority of accommodations provided to employees with disabilities costs less than \$50.00." He then goes on to cite examples from the Job Accommodation Network (JAN) experience.

A comparison of those individuals working in competitive employment with those who are not will provide some notion of how employers have responded in a state to employing people with developmental disabilities.

*** Changing population demographics provide an opportunity for people with developmental disabilities to work.**

The Hudson Institute projects major changes in the work force between now and the year 2000. "The population and the work force will grow more slowly than at any time since the 1930s. The average age of the population and the work force will rise, and the pool of young workers entering the labor market will shrink" (Johnston & Packer, 1987).

The baby-bust will create a shortage of workers to meet these needs. Between 1940 and the early 1980s the median population age ranged between 28 and 30. In 1985 it had reached 31.2; by 2000 it is expected to be 36.3, and by 2050 41.6 (Vachon, 1987). The

impact on the economy will include a slower rate of economic growth, a tighter labor market, and an increased demand for income-sensitive products such as restaurant meals, luxury goods, travel, tourism, and health care (Johnston & Packer, 1987).

The potential benefit for people with disabilities is reflected in the following statement, "Companies accustomed to hiring young workers at cheap wages may find that they must raise wages, reach further down the labor queue, invest in labor-saving technology, or all three, in order to prosper. Food service may be particularly affected" (Johnston & Packer, 1987).

Slower population growth will result in less demand for population-sensitive goods. This trend will contribute to a slowing in economic growth; however, a policy that increases the proportion of the population with disposable income can blunt this trend. Providing employment to those segments of the population who are thought of as "disadvantaged" opens new consumer markets.

A major hurdle that a full employment policy must face is that the jobs of the future will require a more highly skilled and better educated labor force (Johnston & Packer, 1987). Since women, minorities, and immigrants are seen as the potential groups from which labor force expansion must come, it is essential that they have the requisite education and training for these new positions. The same is true for people with disabilities; however, certain disabilities may act as an impediment to these new high skilled jobs. One of the challenges of the 1990s is to carve out those jobs that through accommodations and other supports can be successfully accomplished by people with severe disabilities.

* A changing economy provides new employment opportunities for people with developmental disabilities.

The nature of "employment" is in the process of change. New jobs are replacing old; new forms of work sites are evolving (cottage industries); a service industry is replacing a manufacturing one; home-based occupations are on the rise; employees are

acting more and more like entrepreneurs. (Alvin Toffler's [1980] The Third Wave discusses many of these emerging patterns.) New forms of employment are also beginning to emerge. Home occupations are coming into vogue as workers attempt to balance household activities and careers. The United States has lost its competitive edge over the rest of the world and, as American industry struggles to regain that edge, the labor force will be affected. The work force is aging. There will be greater "disadvantaged" populations. "The economic dependency ratio (the proportion of the population not in the labor force compared to those in the labor force) will continue to drop" (Johnston & Packer, 1987). From the 1.5 dependents per working person, there will be less than 1 dependent per worker in the year 2000.

At a state and local level it is likely that there is a relationship between the overall health of an area's economy and its ability to employ and sustain people with developmental disabilities. High unemployment will probably mean fewer job opportunities for people with developmental disabilities.

Today there is example after example of private efforts to employ people with developmental disabilities. For people with primarily severe physical disabilities, technology is playing a major role in employment of people with disabilities. The Hudson Institute points out that, "The majority of occupations that are being reshaped by these technologies are in the fastest-growing job categories: law, sales and telemarketing, information management, financial services, health care, and leisure and travel services" (Hopkins et al., 1988).

*** Government supports some successful programs proving that people with developmental disabilities can work.**

Many vocational service providers have successfully converted their programs to supported and competitive employment as witnessed by the 15,459 people with developmental disabilities who participated in supported and competitive employment in 1988 (Braddock et al., 1989). This represents about five percent of the total people served

in day programs funded by the nation's state mental retardation and developmental disability agencies. Five or six years earlier the percentage would have been zero, or close to it.

An analysis of the Supplementary Security Income Program paints a similar picture (NADDC, 1989). There has been progress for people with developmental disabilities gaining and maintaining employment. The Section 1619 provisions of the Social Security Act protecting cash and medical benefits for Supplementary Security Income (SSI) recipients who are working became permanent in all states on July 1, 1987. Between September 1987 and September 1988 the number of individuals on the SSI program who earned income sufficient to qualify them for the benefits and protection of the 1619(a) program increased from 12,752 to 17,813 or 40 percent. During the same period their average monthly employment earnings increased from \$478 to \$512 or 7.1 percent. A total of 33,506 people with serious disabilities had significant earned income under both the 1619(a) and 1619(b) programs. In March 1987, 0.61% of those people aged 18 through 64 receiving Supplementary Security Income had earned income sufficient to qualify for 1619(a) or (b) protection. By September of 1988 that participation rate had jumped to 1.57% or 150 percent. There is no reason to expect this upward trend not to continue into the foreseeable future. Fifty to seventy-five percent of those individuals have disabling conditions generally associated with developmental disabilities.

The initiatives undertaken by the Office of Special Education and Rehabilitative Services of the Department of Education have resulted in changing expectations on the part of consumers and advocates in the disability community.

New models (for transition, supported, and competitive employment) have been developed, implemented, and evaluated (Woods & Vandergoot, 1987). Perhaps the best example are the 26 system change grants provided to states to help them implement supported employment sponsored by the Office of Special Education and Rehabilitation Services.

The important point of the data is that people with developmental disabilities are working and are productive. In fact, 1619 participants have a projected combined annual income of \$247 million. As this figure grows, the economic purchasing power of people with severe disabilities will grow as well. The average monthly income for a 1619(a) participant was over \$500 for the month of September 1988 (\$6,000 annualized). These individuals also received an SSI check and their medical needs were paid for by Medicaid. Individuals with disabilities who are employed have the potential economic freedom to choose where they live, what clothes they wear, what consumer goods they buy, etc. Over time, average income will increase and the number of people with developmental disabilities in the labor force will increase. Each individual's opportunities for independence and integration into the community will increase as well.

Results of the Montana 1988 study show wages for supported employment positions range from less than \$1 to \$5.99/hour (Table 7). The average wage is \$3.27/hour. Over one-half of the clients earn between \$3.00 to \$3.45/hour. Almost one-third earn between \$3.50 to \$5.99/hour. According to the responses, 59% of work placements are optimal. In general, clients are more optimally placed than not (Table 8). According to Table 9, it appears that individual placements are more optimal than the other placement options. For example, 58% of the clients on a mobile work crew, 67% of the clients working in an enclave position, and 67% of the clients in transitional employment placements are considered as working in a non-optimal placement.

More paid working hours was most frequently cited as the primary change needed to improve a client's supported employment placement (Table 10). Forty percent of the clients who are not in supported employment are employment appropriate but not placed. Primary service providers indicated an individual may not be in supported employment because there are: no job sites (21%), a lack of staff or agency support (e.g., a job coach, 21%), not enough available funds (11%), or because they have inappropriate behaviors (11%) or lack vocational skills (10%).

*** Most government efforts seriously miss the mark.**

The \$11.4 billion industry (Braddock et al., 1989) of providing day and residential services to people with developmental disabilities represents part of a major economic force in shaping federal and state disability policies and programs. To this figure must be added all the other state and federal programs not included in state mental retardation and developmental disability budgets. Berkowitz, as reported by Vachon (1987), estimates that, "Where in 1970, about \$24 billion was spent on persons with disabilities (for cash incomes, medical care, and other services), \$122 billion was similarly spent in 1982, a 400 percent increase in only 12 years." The economic and organizational power of these programs poses a serious problem for people with developmental disabilities who wish to be independent of this industry which in turn is dependent upon these very same individuals for its survival. To move people into the competitive job market represents a major potential losses in revenue for the providers of day services. According to Braddock, there were 287,697 people with developmental disabilities in day/work programs. Applying the per client cost for supported employment initiatives of \$4,473 to this larger population, the cost is projected to be \$1.2 billion, and this figure excludes many other populations who receive vocational services. Vocational service providers have a multi-billion dollar industry to protect.

William Kiernan has now done two national surveys of providers of vocational services (Kiernan et al., 1988). A disturbing trend seems to have occurred from 1985 to 1986. The percentage of people served in sheltered employment (employment in work environments where only people with disabilities are employed and where payment is customarily at less than the minimum wage) remained unchanged, but there was a decline in those being served in transitional (employment which provides time-limited support leading to competitive employment and where payment is often less than the minimum wage), supported (employment which requires intensive ongoing support, in work environments where people without disabilities are employed and where payment is often less than the minimum wage), and competitive employment (unsubsidized employment

where payment is at or above the minimum wage) programs. From a program participant status, this decline is most unfortunate. The average sheltered workshop weekly wages are \$47 and \$27 for full- and part-time work, respectively. These averages were dramatically higher for those in transitional, supported, and competitive employment (transitional, \$110 and \$48; supported, \$117 and \$51; competitive, \$154 and \$77). (These data are consistent with the Supplementary Security Income figures for average wages presented in Technical Bulletin No. 11.) Hours worked and hourly wages were similarly higher than in sheltered employment. The 1986 data showed that adults with developmental disabilities were placed in programs as follows: sheltered, 57.6%; transitional, 4.5%; supported, 4.1%; and competitive, 8.4% employment. It is puzzling why so many people with developmental disabilities would choose sheltered employment over the three other more economically rewarding alternatives!

Reducing the number of people in sheltered employment is threatening to providers of the sheltered employment and day programs. (Indirectly, it is an attack on certain residential programs as well.) It also challenges other employment services such as Vocational Rehabilitation, Jobs Training Partnership Act, and Employment Security to begin to seriously serve a population that in the past they have not. Without strong federal and state leadership or strong consumer demands, it is unlikely that these fledgling efforts can be maintained.

Many vocational services and supports available to people with developmental disabilities do not have an explicit goal of "real jobs for real pay." People living in institutions and sheltered communities do not have access to the labor market. State institutions and residential communities tend to be geographically isolated from economic centers. The training and educational services offered tend to be of a "pre-vocational" nature bearing little resemblance to real jobs. Sheltered workshops are no better. People often work for pennies a day, segregated from workers without disabilities, with no hope for a better future. Other individuals work in similarly unintegrated subsidized settings in which economic productivity is not a major concern. While some people with

developmental disabilities are in programs that provide competitive or supported employment, too many individuals are being deprived because of these established patterns.

Joseph Stubbens, author of "Towards a National Policy on Vocational Rehabilitation" (1987), points out that professional rehabilitationists are concerned about "the wisdom and strategic value of accommodating to the current socio-political climate in the interests of protecting the fiscal position of VR programs and containing possible cutbacks." Professor Stubbens concludes with the optimistic statement, "There are signs for redefining VR as integral to a just society rather than as a technical handmaiden to the labor market and other special interests."

Important segments of the disabilities community do not accept the basic premise that people with developmental disabilities can engage in productive activities and, more specifically, that people with developmental disabilities can be employed in the conventional sense of the term. These segments include families of people with developmental disabilities, service providers, agency heads, and political leaders.

*** Programs are poorly organized and fragmented.**

Federal employment programs are not organized to facilitate employment of people with severe disabilities into the new industries and jobs that are emerging. It bears repeating that in 1978 41.1% of those with work disabilities were employed (Vachon, 1987). Six years later, in 1984, only 42.5% were employed. During the same six-year period, there was over a 9% growth in jobs (Bureau of Labor Statistics) that more than offsets the 3% growth in employment by people with disabilities. From the point of view of the person with a disability, "the majority of disabled persons who have gone through vocational rehabilitation say that it provided little or no help to them in finding a job" (Taylor et al., 1987). While sixty percent of the people surveyed are familiar with vocational rehabilitation, only 13% have used them (Taylor et al., 1987).

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Structurally, vocational rehabilitation services are poorly suited to providing the ongoing supports required by many people with developmental disabilities since VR services are time-limited. While 63% of vocational rehabilitation cases were classified as severe and 62% were successfully rehabilitated, the definition of severe is very broad and includes many individuals who would not qualify as developmentally disabled (NADDC, 1989). Vocational rehabilitation agencies are allowed to show a placement into a sheltered workshop as successful placement (Status 26); however, the actual information on "successful placements" is not reported by type of employment or wages earned, although that information is available. Supported employment funds represented less than 2% of the Vocational Rehabilitation budget for federal fiscal year 1988.

The Jobs Training and Partnership Act (JTPA) lacks a focus on or commitment to people with severe disabilities as well. Only about 12% of program participants are classified as "handicapped," let alone severely or developmentally disabled. Clearly, there is a relationship between poverty and disability. Researchers have suggested that 26% of persons with work handicaps were at or below the poverty line in 1978, and that as much of 70% of the poverty among some groups is the direct result of disability (Vachon, 1987). If these figures have any validity at all, one would expect a much higher percentage of people with disabilities to be served. More importantly, the JTPA is not set up to provide the job accommodations and long-term supports often needed by people with developmental disabilities.

Braddock's 1988 survey of state mental health and developmental disability agencies indicates that only 5.4% of the people enrolled in day/work programs are in supported/competitive employment programs (Braddock et al., 1989). Kiernan's 1986 data shows a higher (but declining over the prior year) participation rate at 12.15% (Kiernan et al., 1988). (These differences are probably due to the high numbers of institutional residents included in Braddock's data.) These positive, but limited, efforts for fewer than 16,000 people pale in comparison to the estimated 10 million people aged 18 through 64 in the county with work disabilities (Griss, 1988). (Work disabilities are those that prevent

or limit a person's employment.) A significant portion of these ten million people will have severe disabilities and will require ongoing supports. To date, the costs of these supports have been grudgingly borne by state mental health and developmental disabilities agencies.

Employment Security agencies, while providing unemployment compensation and job services, have little experience in serving people with developmental disabilities. They have no mandate to work with employers to develop supports or services for people with developmental disabilities. Employment Security agencies are the scorekeepers for employment, but they do not include people with disabilities. Consequently, this systemic fragmentation results in a lack of reliable and valid information about employment of people with severe disabilities. Just as Vocational Rehabilitation agencies can exclude individuals whose disability is too severe to be rehabilitated, Employment Security agencies have a responsibility to only pay unemployment benefits to people who are available and able to work. Policy-makers need to be concerned about how these terms are defined.

Consumers' experience with vocational rehabilitation can be assessed by analyzing consumer survey responses to Services and Satisfaction, 10b. A further analysis is provided by an analysis of Services and Satisfaction, question 11, vocational services (4.0) section.

*** Programs are poorly planned and targeted.**

The governmental service system (both state and local) currently lacks the resources and mandate to provide ongoing employment supports to people with developmental disabilities. One of the difficulties in securing such a mandate is the lack of a single state or federal program or agency focused on the employment of people with developmental disabilities (NADDC, 1989). Individuals and organizations that have attempted to secure such a mandate heretofore have had to rely upon coalition building as a strategy. Coalition building, inter-agency agreements, and similar approaches are unlikely to be effective in all states. The result of the current situation is fragmented policy and an inability to address the several interlocking and interacting issues that must be

simultaneously addressed. These issues include: training, placement, individual worker supports, employer and employee placement, family and provider resistance, benefits, employment discrimination, income subsidies, etc. The multiple agencies and programs concerned with employment policy and programs are a formidable barrier to the implementation of an employment initiative for people with developmental disabilities.

A thorough and enlightening discussion of the issues surrounding vocational policy for people with disabilities is contained in The Changing Nature of Work, Society, and Disability: The Impact on Rehabilitation Policy (Woods & Vandergoot, 1987). The various authors of articles in this book conclude that the United States has failed to develop a coherent policy for employment of people with disabilities who will become a more important part of the labor force as we enter the 21st century. They point out that people with disabilities will increase in the population due to advances in medical technology while at the same time the total population is rapidly aging. The result is greater job opportunity for people with disabilities. They point to statistics that suggest that unemployment among people with disabilities has increased, indicating that the policies and programs of vocational rehabilitation have failed.

Joseph Stubbens, whose article "Towards a National Policy on Vocational Rehabilitation" (Stubbens, 1987) serves as a conclusion to the book, suggests that scientific and technological progress allows us to "think of a person with a disability as one having a disadvantaged relation to society." Such a definition forces "an interdependent view of society and would seek remedies in the sociopolitical realm." One of the challenges of the 1990s is to carve out those jobs that through active placement, accommodations, supports, and special training can be successfully carried out by people with developmental disabilities.

* Swelling the ranks of the unemployed with disabilities are youths recently transitioned from high school programs into the competitive workplace without marketable skills.

Since 1979, more than 2.5 million youths with disabilities have graduated from the public school system in our country. Of that number, only 23% are competitively employed or in post-secondary training. Students with mental retardation and learning disabilities typically represent between 50-69% of the population designated as handicapped in public schools (Project PERT, 1985). The concept of learning disabilities applied to issues of vocational needs and supported employment is relatively new. Studies done in states like Arizona and Pennsylvania (Project PERT, 1985) suggest that between 45-60% of adults with learning disabilities were unemployed and needing rehabilitation services.

During the month of September 1988, the Montana University Affiliated Program Satellite conducted, through a contract with the Montana Supported Employment Demonstration (MSED) Project of the Department of Social and Rehabilitation Services, a telephone survey on supported employment opportunities and needs in Montana high schools. The survey included 35 high schools out of 163 high schools, providing a 21.4% sampling of Montana high schools. These schools represent both metropolitan and rural communities throughout Montana. The information on each high school was provided by special education administrators and educators. The target population for this survey was **seniors in self-contained or resource room programs who graduated in Spring 1988.**

The students with learning disabilities (LD) and mental retardation (MR) represent 96% of the total group surveyed. Of the 237 students with learning disabilities, nearly 21% were reported to be in supported employment situations. An additional 38% were appropriate for but not placed in employment situations. Thus, 59% are either in or appropriate for supported employment activities. Forty-one percent of the surveyed group were viewed as not appropriate for supported employment by those responding to the survey.

Of the 52 students with mental retardation surveyed, 75% were in supported employment situations. An additional 10% were appropriate for but not placed in

employment situations. Thus, 85% are either in or appropriate for supported employment activities. Fifteen percent were viewed as not appropriate for supported employment.

Annually, the Montana State Office of Public Instruction tabulates the number of handicapped students by age and handicapping condition for federal reporting purposes. As of December 1, 1987, there were 1,421 students with learning disabilities 16 years of age and older receiving services. There were 299 students with mental retardation in this same age range receiving services. Using the percentages derived from the September 1988 MSED Telephone Survey, 59% of the LD group (838) and 85% of the MR group (254) are appropriate for employment-related activities and experiences. However, in the LD group only 21% (298) could be expected to be placed in actual supported employment. For the MR group, 75% of the 299 (224) could be expected to be placed in actual supported employment. This information is presented in the Table 11 (Offner, Arnold, Wittekiend, 1989).

NADDC RECOMMENDATIONS

1. A coherent policy on the employment of people with developmental disabilities should be developed for the United States. Such a policy should have a particular emphasis on those people with severe life-long disabilities. The policy should recognize that these individuals have "a disadvantaged relationship with society" and the function of the policy is to create employment for this population by changing their relationship with society. It is not enough to simply "rehabilitate" the individual. Society and the economy must be rehabilitated as well. Such policy development cannot be relegated to those with a vested interest in the status quo or simply getting a piece of the action. Vocational policy development must concentrate on inventing a future for people with disabilities, and it must take into account the broader social and economic future of the country. States need not wait for national leadership. They, too, are capable of policy development and in many respects may be more successful because they can account for local and

regional social and economic differences better than the federal government can. Both federal and state policy development efforts must be cautious of the vested interests of the traditional programs and the professionals who are responsible for them.

The development of a vocational policy requires that it have at its heart a specific, challenging, but achievable goal such as: achieving the same rate of employment and labor force participation for people with developmental disabilities between the ages of 18 and 64 as for the general population by the year 2000.

2. All programs for employing and training people with disabilities should have a central federal focus. There must be the authority to collect data on employment and labor force participation by people with disabilities. These data should be reported along with current labor statistics by functional and diagnostic characteristics of the disability. In order to achieve high visibility for employment of people with disabilities, the federal and state governments should establish these offices at the highest possible level within the agencies selected. Responsibilities of such an office would include: developing employer incentive programs, vocational education, training, and rehabilitation, employer and employee subsidies, provision of short- and long-term job supports, data collection and monitoring, planning, research, and evaluation. Planners and advocates have looked to the Medicaid program as the primary federal funding mechanism for services to people with developmental disabilities. While politically expedient in the short-term, over the long-term health programs should not be used to meet other service and support needs. Clear programmatic goals and means to achieve them are required to address the issue of employment for people with developmental disabilities. It is difficult to see how a medically-oriented agency (Health Care Financing Authority) could be expected to master employment policy along with the equally critical health policies. It seems that government services can be organized in two fundamental ways: by similar services or by similar populations. Each has its advantages.

Organizing by populations makes accountability easier but results in a fragmentation and duplication of services. Further, it leads to a segregated service system. Organizing by similar services results in a more integrated service system, but spreads accountability over several agencies.

3. Developmental disabilities councils, advocacy groups, and others with an interest in a full-employment agenda for people with developmental disabilities should take their cause directly to the employers of this country. There are numerous employer-sponsored initiatives already in place. Fortunately, industry is reaching a point where it is in its own best interest to hire and train people with disabilities. The best spokespeople in undertaking this initiative are working people with developmental disabilities and their employers. The advantage of this approach is the traditional reluctance that many employers have to get involved with government programs. This strategy will eventually place government programs in a clearly supporting role for the employer and the employee, not the traditional middle-man role that they now play, often to the frustration of the employer, the person with a developmental disability, and the person's family.
4. The Rehabilitation Services Administration should require all state VR agencies to indicate those individuals who have developmental disabilities in its statistics.
5. The Rehabilitation Services Administration should provide additional supported employment funding that is not time-limited for people with severe and life-long disabilities (e.g., developmental disabilities). These funds may not be commingled with any other VR accounts at the state or federal levels.
6. The Jobs Training and Partnership Act administration should require JTPA state service providers to indicate consistently with VR those individuals who have developmental disabilities.
7. The Department of Labor should require that all state Employment Security agencies report (as they do with veterans, women, and racial minorities) the number

and percentages of people with developmental disabilities served and profile this population as others are.

8. State agencies should require vocational service providers (including state-operated programs and facilities) to report wages, hours worked, types of employment, and types of businesses employing individuals with developmental disabilities. Monthly, or at least annual, reports should be published that compare service providers, types of vocational programs, and regions of a state.

MONTANA RECOMMENDATIONS

The primary source for Montana's recommendations is the Temple University Consumer Survey conducted by our state in 1989. Recommendations derived from the survey are followed by parenthetical reference to specific item numbers in the survey, indicating the percent of respondents dissatisfied with a particular service and the total number of respondents to that particular item. If the issue also arose during the public forums, that source is noted in the parenthetical reference as well.

1. Funding and opportunities for persons with disabilities to participate in supported employment programs in rural settings must be expanded to include a broader range of clients (forums).
2. Information regarding regulations for maximum allowable income and other specifications as they relate to SSI benefits must be more readily available and comprehensible (forums).
3. A method for filing the required court reports by representative payees needs to be developed which is not overly expensive. (forums)
4. Integrated adult day services must be increased, more appropriately suited to the clients' needs (4.2: 19.4% of 31; 4.5: 66.7% of 3).
5. Facility-based sheltered employment, work activities or prevocational services need to be available in sufficient quantities to make both the work and the resulting pay

rewarding and beneficial and appropriately suited to individuals' needs (Item 4.6: 23% of 22; Item 4.8: 25% of 12; forums).

6. Need for increased assistance in area of financial management services should be increased (6.19: 31% of 13).
7. Need for individuals to be productively engaged in work or work-like life activities. It is important for policy-makers to place an emphasis on funding activities which creatively develop functional real-world work activities for persons with disabilities.
8. Strong need to address employment programs and training opportunities for the learning disabled population as they transition from high school into the work world. Under the current system it is difficult to obtain services for these individuals after they leave school. The educational program for students with learning disabilities typically focuses on academic assistance with very little emphasis on supported employment and preparation for the world of work. As a consequence, many of our learning disabled students are not employed after high school.
9. The Social Security Title II guidelines which define Substantial Gainful Activity (SGA) must be revised to encourage persons with disabilities to increase their work level. Currently the SGA is set at \$300.00 per month. Most employees in supported employment programs fall under those guidelines. Essentially, persons with disabilities earning approximately minimum wage cannot work more than 22 hours per week ($\$3.35 \times 22 \text{ hrs.} \times 4 \text{ wks.} = \$294.89/\text{mo}$) or they will stand to lose their benefits because they are then over SGA. We are therefore saddled with a regressive system which threatens the pride, confidence, and integration of persons with disabilities into the work-place, jeopardizing their benefits for earning too much.

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APPENDIX E

FIGURES AND TABLES

TABLE 6

AGE RANGES	CLIENT'S PRIMARY DISABILITY										Total # (%)
	Phya. Dis.	Sens. Impair.	Mental Ret.	Brain Inj.	Mental Ill.	Learn. Dis.	Comm. Dis.	C.P.	Seiz. Dis.	Aut. Like	
	# (%)	# (%)	# (%)	# (%)	# (%)	# (%)	# (%)	# (%)	# (%)	# (%)	
(Usable Responses)	(N=11)	(N=4)	(N=423)	(N=13)	(N=126)	(N=24)	(N=1)	(N=6)	(N=3)	(N=2)	(N=61)
16 - 20 Years	1(9)	1(25)	48(11)	1(8)	3(2)	9(38)	0	1(17)	1(33)	2(100)	67(11)
21 - 25 Years	3(27)	0	97(23)	2(15)	12(10)	6(25)	0	2(33)	1(33)	0	123(20)
26 - 30 Years	0	1(25)	89(21)	4(31)	28(22)	5(21)	1(100)	2(33)	0	0	130(22)
31 - 35 Years	1(9)	1(25)	67(16)	1(8)	26(21)	3(13)	0	0	0	0	99(16)
36 - 40 Years	4(36)	0	49(12)	2(15)	27(21)	0	0	0	1(33)	0	83(14)
41 - 45 Years	1(9)	1(25)	26(6)	2(15)	9(7)	1(4)	0	1(17)	0	0	41(7)
46 - 50 Years	1(9)	0	21(5)	0	11(7)	0	0	0	0	0	33(5)
51 - 55 Years	0	0	21(5)	1(8)	7(9)	0	0	0	0	0	29(5)
56 - 60 Years	0	0	0	0	0	0	0	0	0	0	0
61 - 65 Years	0	0	4(1)	0	2(2)	0	0	0	0	0	6(1)
66+ Years	0	0	1(<1)	0	1(1)	0	0	0	0	0	2(<1)

TABLE 7

CLIENT'S HOURLY RATE OF PAY	CLIENT'S PRIMARY DISABILITY								Total # (%)
	Phys. Dis.	Sena. Impair.	Mental Ret.	Brain Inj.	Mental Ill.	Learn. Dis.	C.P.	Seiz. Dis.	
	# (%)	# (%)	# (%)	# (%)	# (%)	# (%)	# (%)	# (%)	
(Usable Responses)	(N=4)	(N=2)	(N=166)	(N=6)	(N=57)	(N=15)	(N=2)	(N=3)	(N=255)
\$.01 - \$.99/hr	0	0	7(4)	0	0	0	0	0	7(3)
\$1.00 - \$1.49/hr	0	0	2(1)	0	0	0	0	0	2(<1)
\$1.50 - \$1.99/hr	0	1(50)	6(4)	0	0	0	1(50)	0	8(3)
\$2.00 - \$2.49/hr	0	0	11(7)	0	3(5)	0	0	0	14(5)
\$2.50 - \$2.99/hr	1(25)	0	13(8)	2(33)	2(4)	0	0	0	18(7)
\$3.00 - \$3.49/hr	2(50)	1(50)	87(52)	2(33)	31(54)	7(47)	0	1(33)	131(51)
\$3.50 - \$3.99/hr	0	0	25(15)	0	9(16)	3(20)	0	1(33)	38(15)
\$4.00 - \$4.49/hr	0	0	11(7)	2(33)	11(19)	2(13)	0	1(33)	27(11)
\$4.50 - \$4.99/hr	0	0	3(2)	0	1(2)	1(7)	1(50)	0	6(2)
\$5.00 - \$5.49/hr	1(25)	0	1(<1)	0	0	1(7)	0	0	3(1)
\$5.50 - \$5.99/hr	0	0	0	0	0	1(7)	0	0	1(<1)

1A.

TABLE 8

IS THE CLIENT'S SUPPORTED EMPLOYMENT PLACEMENT OPTIMAL?	CLIENT'S PRIMARY DISABILITY								
	Phys.	Sens.	Mental	Brain	Mental	Learn.		Seiz.	
	Dis.	Impair.	Ret.	Inj.	Ill.	Dis.	C.P.	Dis.	Total
	# (%)	# (%)	# (%)	# (%)	# (%)	# (%)	# (%)	# (%)	# (%)
(Usable Responses)	(N=3)	(N=2)	(N=164)	(N=6)	(N=55)	(N=16)	(N=2)	(N=3)	(N=251)
Yes	3(100)	1(50)	94(57)	6(100)	28(51)	12(75)	1(50)	2(67)	147(59)
No	0	1(50)	70(43)	0	27(49)	4(25)	1(50)	1(33)	104(41)

TABLE 9

CLIENT'S EMPLOYMENT SITUATION	IS THE CLIENT'S EMPLOYMENT PLACEMENT OPTIMAL?		
	Yea	No	Row
	#(%)	#(%)	Total
Individual Job Placement	112(77)	50(50)	162(100)
Mobile Crew	29(20)	40(40)	69(100)
Enclave in Industry	3(2)	6(6)	9(100)
Transitional Employment Placement	2(1)	4(4)	6(100)
Total	146(59)	100(41)	246(100)

TABLE 10

CHANGE NEEDED TO IMPROVE A CLIENT'S EMPLOYMENT SITUATION	# (%) OF CLIENTS
<hr/>	
(Usable Responses)	(N=112)
More Paid Working Hours	68(61)
Individual Employment Situation	20(18)
More Job Training	7(6)
Better Pay	7(6)
Transportation	5(4)
Other	5(4)

TABLE 11

DISTRIBUTION OF GRADUATING 1988 SENIORS FROM
SELF-CONTAINED OR RESOURCE ROOMS AND THE TYPE OF
SUPPORTED EMPLOYMENT/EMPLOYMENT RELATED SERVICES RECEIVED

Primary Disability	In S.E.	Approp for/ Not in S.E.	Not Approp for S.E.	Total
<hr/>				
Learning Disability	49	91	97	237
Mental Retardation	39	5	8	52
Emotional Disability	3	1	-	4
Orthopedically Impaired	1	-	-	1
Multiply Handicapped	2	-	3	5
Visually Impaired	1	-	-	1
TOTAL	95	97	108	300

CHOICE OF JOB

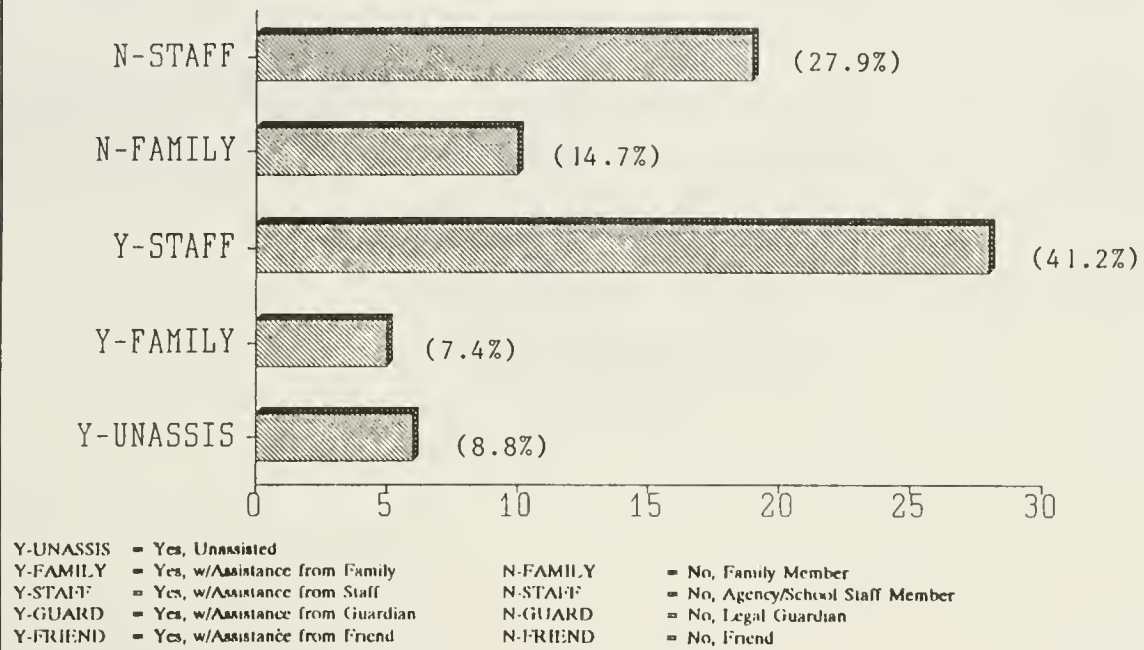


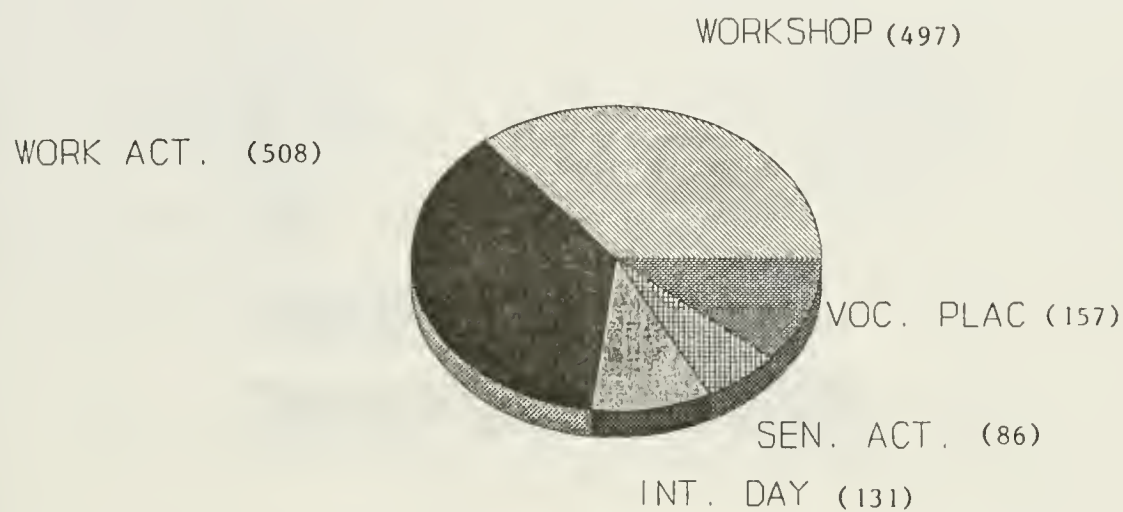
FIGURE 23

Consumer Survey 1989

Level of Satisfaction with Services - Employment

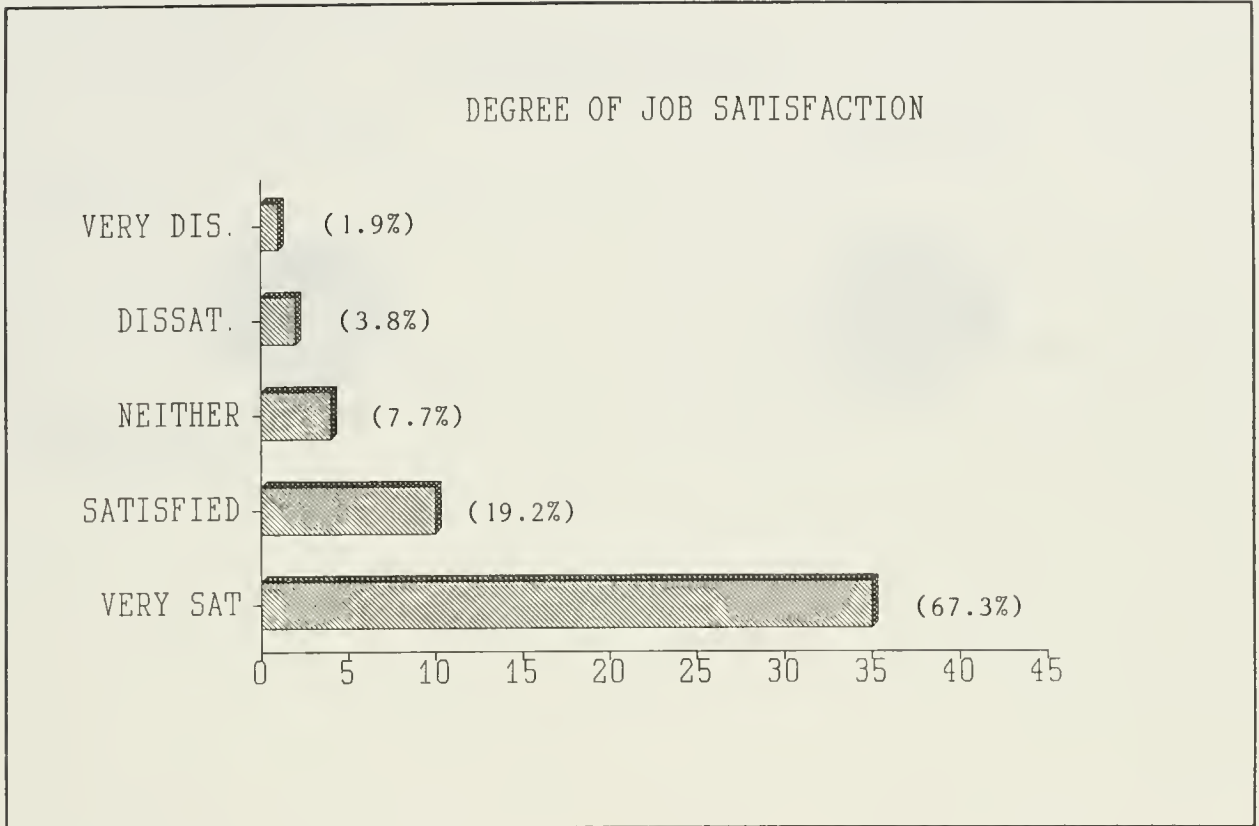
<u>Service</u>	Percentage of Participants Receiving <u>Services</u>	% Satisfied of those Receiving <u>Services</u>	% Dissat. of those Receiving <u>Services</u>
<u>Vocational & Other Day Services</u>			
Adult Day Service (Developmental)	35%	82%	18%
Work Activity	26%	76%	12%
Sheltered Employment (facility based)	17%	76%	24%

COMMUNITY BASED VOCATIONAL SETTINGS, 1989



SEN. ACT.	= Senior Day Program
WORK ACT.	= Work Activity Habilitation
INT. DAY	= Intensive Adult Habilitation
WORKSHOP	= Sheltered Workshop
VOC. PLAC	= Individual Job Placement

FIGURE 24

**FIGURE 25**

Consumer Survey 1989

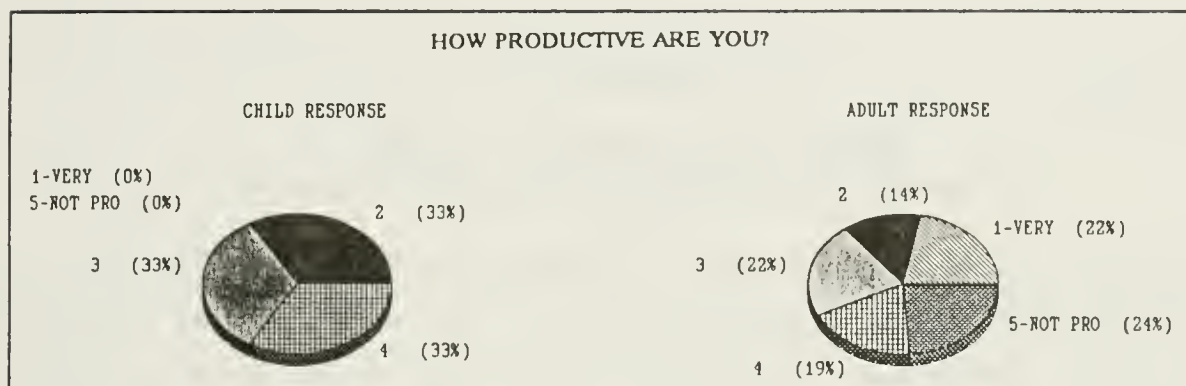


FIGURE 26
Consumer Survey 1989

INCOME

A VISION OF ADEQUATE INCOME FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

The need for income is fundamental in modern society. People need income sufficient to provide for their basic needs and to maintain an adequate standard of living, as well as to provide opportunities to save for old age and for emergencies. Most people obtain income by working. Adults unable to work and children dependent on people who are unable to work require income-related assistance, either through welfare payments or insurance benefits. Income supports must be available when needed, for both emergency/short-term and long-term needs. People should not be forced to live below the poverty level because of the inadequate income support, and amounts of needed supports should be linked to individual and family needs. Income support should be provided in ways that foster dignity and increase independence and autonomy, including opportunities to obtain and maintain employment.

At different times in people's lives it becomes necessary to rely on some form of income support to survive: people lose jobs, become ill, have accidents, have to provide for elderly parents, or have extraordinary needs. People with developmental disabilities and their families in such situations need additional income because of the higher costs associated with having a developmental disability and the proportionately greater need to buy other types of supports and assistance for the individual and the family. The severity of the disability frequently defines the level of related costs and the likelihood of poverty. Some individuals with developmental disabilities may need long-term income support, from infancy through old age; others may require only occasional short-term income support. Regardless of the duration of the assistance, people with developmental disabilities should have access to income supports which are flexible enough to meet individual needs and are complementary to supports for employment and productivity. Levels of support must be sufficient to maintain adequate standards of living, including additional resources needed specific to the disability. Eligibility criteria for means-related income support programs

should take into consideration the exceptional costs faced by people with developmental disabilities and their families.

FACTS

* Individuals with disabilities are twice as likely to live in a low-income household (\$15,000 or less) as households which do not include a person with a disability. People with the most severe disabilities are the most likely to live in low income households; 63 percent of individuals with very severe disabilities were in households with incomes of less than \$15,000 in 1984 (Taylor, Kagay, and Leichenko, 1986).

* The number of people living in poverty increased significantly between 1979 and 1987, from 26.1 million to 32.5 million. The largest contributing factor was the reduced effectiveness of means-tested welfare programs (such as SSI and Aid for Families with Dependent Children), which accounted for 36 percent of the increase; followed by population growth (26 percent); net reduction in income from employment of "market income" (13 percent); reduced effectiveness of social insurance programs, such as SSDI (11 percent); and the reduced effectiveness of federal tax policy (5 percent), according to an analysis conducted by the Congressional Research Service. The average income for the lowest fifth of the population dropped nearly 11 percent from 1973 to 1987; average income for the top fifth rose 24 percent during the same period. Most of the change occurred between 1979 and 1987 (Committee on Ways and Means, U.S. House of Representatives, 1989).

* Increased poverty among people with disabilities has also been affected by tightened disability insurance eligibility, as well as by the factors associated with general increases in poverty (Committee on Ways and Means, U.S. House of Representatives, 1989).

* Many people with disabilities who need income supports are receiving SSI or SSDI benefits. Many needy people eligible for SSI - especially children - are not receiving benefits. A recent federal court of appeals decision found the SSI eligibility procedures for children too restrictive as used by the Social Security Administration (Ellison, Bradley,

Knoll et al., 1988). Legislation has been introduced (H.R. 868) that would improve procedures for the assessment of disabilities/functional limitations among needy children applying for SSI benefits.

- * Because Medicaid benefits are linked to SSI status the restrictiveness in SSI eligibility for children means that many low income children with disabilities are also not receiving access to needed health care available through the Medicaid program.

- * The federal poverty level in FY 1987 was \$481.50 per month; the average federal Supplemental Security Income (SSI) benefit to people with disabilities in FY 1987 was \$251 per month. Although some states provide supplementary state payments (SSP), many people with disabilities receive only the federal SSI benefit. Mandatory SSP benefits now apply to fewer than 8,000 people nationwide.

- * The Social Security Disability Insurance (SSDI) program, together with the SSI program, provided benefits to over one million individuals with developmental disabilities in FY 1987: an estimated 747,200 people with developmental disabilities representing approximately 27 percent of all SSI recipients on the basis of disability (including blindness); an estimated 522,300 adults with developmental disabilities who receive SSDI benefits' less 203,000 people receiving both SSI and SSDI benefits, for an unduplicated total of 1,066,500 (DHHS, 1988).

- * The Substantial Gainful Activity (SGA) limit on earnings from employment used by the Social Security Administration to determine work-related disability and eligibility for SSI has not been raised from \$300 per month since 1980; the SGA amount for Social Security Disability Insurance (SSDI) recipients who are blind is currently (1989) \$740 per month and increases annually.

- * SSI recipients in Medicaid-supported nursing homes and residential programs receive only a \$30 per month "personal needs" allowance.

- * Despite the success of the Work Incentive (1619) Program in encouraging SSI recipients with disabilities to move into employment, there is no similar program for people with

disabilities who receive SSDI, although legislation has been introduced in the 101st Congress to address this.

Input gathered during Forums in Montana identify the Social Security Title II guidelines which define Substantial Gainful Activity (SGA) as discouraging persons with disabilities from increasing their work level. As noted above, currently the SGA is set at \$300.00 per month. Most employees in supported employment programs fall under the SGA guidelines. Essentially, persons with disabilities earning approximately minimum wage cannot work more than 22 hours per week ($\$3.35 \times 22 \text{ hrs.} \times 4 \text{ wks.} = \$294.89/\text{mo}$) or they will stand to lose their benefits because they are then over SGA. We are therefore saddled with a regressive system which threatens the pride, confidence, and integration of persons with disabilities into the work-place, jeopardizing their benefits for earning too much.

Supplemental Security Income (SSI): An income maintenance program for needy individuals who are elderly, blind, or meet federal disability criteria, providing monthly payments (based on amounts determined federally) that result in incomes well below the federal poverty level. The ability to earn more than \$300 per month in employment is considered evidence that the person does not have a disability and is therefore ineligible.

Social Security Disability Insurance (SSDI): A benefit paid to individual workers who become disabled and have worked long enough to reach federal Social Security eligibility or their dependents or the "adult disabled child" of retired, deceased or "disabled workers" covered by Social Security. SSDI benefits for "disabled workers" are considerably higher than those in the SSI program average \$530 per month in 1988. The average monthly benefit under the "disabled adult child" program was approximately \$300 in 1988. Approximately 21.3 percent of the 43,035 SSDI beneficiaries added to the rolls in 1985 and identified as people with a developmental disability qualified as "disabled workers" (Robertson, 1989).

Section 1619: A work incentive program designed to encourage SSI recipients with disabilities to become employed without the abrupt loss of SSI and Medicaid, by providing continuing SSI and Medicaid eligibility even if earnings rise to the point that no SSI payment is made. Since the program was made permanent by the Employment Opportunities for Disabled Americans Act (P.L. 99-643), effective July, 1987, the participation rate has increased nationally from less than 0.10 (percent in September, 1987, to 1.57 percent in September, 1988 (Office of Supplemental Security Income, 1988b). In Montana there were 40 participants as of September, 1988, an increase of 666 percent over June of 1987. The 1619 program is not available to SSDI beneficiaries, although the SSDI program does provide for a 45 month period of extended eligibility for beneficiaries who attempt to work. Legislation has been introduced that would extend the 1619 program to SSDI recipients.

Aid to Families with Dependent Children (AFDC): Cash welfare payments to needy children and their mothers (or other caretaker relatives) who have been deprived of parental support or care because their father or mother is absent from home continuously, incapacitated, deceased, or is unemployed. Eligibility, benefit levels, and income and resource limits are set by the individual states and territories, which provide from 20 to 50 percent of the funding. In 1988, for example, the majority of states had AFDC payment standards below 75 percent of the federal poverty level, including 16 between 50 and 74 percent, 24 between 25 and 49 percent, and 4 below 25 percent of the federal poverty level (Task Force on Technology-Dependent Children, 1988). All offer AFDC to needy (as defined by the state) children without able-bodied fathers at home, and 31 also offer federal cash supplements to children in two-parent families who are needy because of the unemployment of one of their parents (Aid to Families with Dependent Children of Unemployed Parents/AFCE-UP). Nationally, benefit levels have failed to keep pace with inflation; the median decline in benefit levels adjusted for inflation was 37 percent from 1970 to 1989.

Recent federal legislation (The Family Support Act of 1988/P.L. 100-485) requires all states to implement a "workfare" program by October 1, 1990. This program requires that adults must register for work and training as a condition of AFDC eligibility. States are currently in transition from the Work Incentive (WIN) program to the Job Opportunities and Basic Skills Training (JOBS) program authorized by P.L. 100-485. Under both the WIN and JOBS programs people who are ill or "incapacitated" or needed in the home because of the illness or incapacity of another member of the household are exempt from participation. There is no strategy included in these requirements for low income people with disabilities to be supported appropriately in the job training program so that they have the same opportunity to get off the AFDC rolls as those with disabilities.

Food Stamps: A federally-funded program to provide assistance to needy individuals and families in their food purchases, with monthly benefits established on the basis of family size and income levels. Under federal law, the definition of family may include unrelated groups of people with disabilities who are living together. The monthly allotment of food stamps provided through the program can be used to some extent at the discretion of the beneficiary; however, purchases are limited to specified food items and must be made with the stamps themselves, thus identifying the person as a food stamp recipients.

CRITICAL ISSUES

- * Payment levels in publicly-funded programs are too low to provide for basic needs. The use of the poverty level as the goal rather than an income level sufficient to provide a basic standard of living is a related critical issues.
- * Even using the poverty level standard (\$11,611 for a family of four in 1987), income support programs fall well below this level.

Social Changes/Demographic Issues

- * The number of people classified as poor increased nearly 25 percent from 1979 to 1987, from 26.1 million to 32.5 million people (Committee on Ways and Means, U.S. House of Representatives, 1989).
- * During the same period the official poverty rate increased from 11.7 to 13.5 percent, while the aggregate "poverty gap" - the difference between a poor family's disposable income and the official poverty level - increased 45 percent of by \$12.8 billion (Committee of Ways and Means, U.S. House of Representatives, 1989).
- * With the exception of people who are elderly, average household income has declined for individuals and families in the lower economic strata while rising consistently for those in the middle and upper income segments. This occurred despite general economic growth in most areas of the country during that period.
- * In 1987, 60 percent of all poor families with children were families in which someone worked during the year - the working poor.
- * There have been some improvements in procedures to determine and review eligibility for federal SSDI and SSI benefits for people with disabilities. Loss of these benefits has been a factor in the increase in poverty and homelessness among people with disabilities.

Policy Issues: Programmatic

- * There is no work incentive program for SSDI recipients comparable to the 1619 program for SSI recipients.
- * Current SSI regulations place some limitations on the ability of SSI recipients to retain benefits if they receive inheritances or housing assistance from their families designed to help them avoid institutional placements, if the amounts received place them above SSI income and resource limits.
- * There is tremendous variation in income supports available through the AFDC program in the absence of any federal minimum standard; in many states the level of AFDC

benefits in considerably below the federally-determined lower standard of living level specific to the state.

Policy Issues: Rights/Access

- * The federal SSI eligibility criteria for children with disabilities are inappropriately excluding many needy children; there are minimal outreach efforts to smooth the application process. Although their eligibility is supposed to be based on the presence of a disability that is comparable in severity to one that would define an adult's eligibility (i.e., the inability to engage in "substantial gainful activity"), children have not received individual assessments of their functional limitations comparable to those provided for adults in the SSI application process.
- * People with disabilities who earn more than \$300 per month/\$3,600 per year (the Substantial Gainful Activity or SGA threshold, unchanged since 1980) are not considered disabled for purposes of SSI eligibility, despite the severity of their actual disability and their need for supplementary income support while attempting to be productive and independent.
- * The SGA level for people with disabilities other than blindness who receive SSDI benefits is \$300 per month, compared to \$720 per month permitted SSDI beneficiaries who are blind.
- * Essentially, persons with disabilities earning approximately minimum wage cannot work more than 22 hours per week ($\$3.35 \times 22 \text{ hrs.} \times 4 \text{ wks.} = \$294.89/\text{mo}$) or they will stand to lose their benefits because they are then over SGA. We are therefore saddled with a regressive system which threatens the pride, confidence, and integration of persons with disabilities into the work-place, jeopardizing their benefits for earning too much.
- * There is no SSI in American Samoa, Guam, Puerto Rico, and the Virgin Islands.

Policy Issues: Fiscal/Resource

- * Especially in the absence of expanded mandates for state supplements, the amount of the federal SSI benefit is totally inadequate in relation to standards of minimal (i.e., poverty level) income support, let alone support at the level of a basic standard of living.
- * AFDC benefit amounts have significantly failed to keep pace with inflation in virtually all states; despite favorable federal matching rates in many states, there is continuing unwillingness to provide state matching funds for increased benefits.

Policy Issues: Data/Monitoring/Accountability

Data on participation and benefits for people with developmental disabilities are available to considerable extent for the SSI, 1619, and SSDI programs. There are virtually no comparable data on generic income support programs such as AFDC and food stamps, nor on the impact of policy changes such as the work registration requirements and the related exemption of people with disabilities among AFDC applicants.

Public Attitudes

- * There continues to be a prevailing attitude that increases in income supports - even up to minimal standards accepted in the public policy realm - contribute to dependency and larger "welfare rolls". Although people with disabilities are frequently not intended to be included in these references, the resultant lack of support for increased benefits adversely affects their chance of moving out of abject poverty.
- * The belief that "welfare" is attractive and thus discourages people from working ignores information such as findings from the Harris poll that 82 percent of people with disabilities receiving benefits as a result of their disability would give them up if they had a job.

NADDC RECOMMENDATIONS

1. The United States should have a national income policy that guarantees a livable income, sufficient to meet the basic needs of all people. The official "poverty line" should be raised to an adequate standard.
2. Both means-tested and "social insurance" programs should be redefined as income support programs, designed to provide sufficient assistance to those in need to enable them to maintain a basic standard of living.
3. Income supports should complement the efforts of people with disabilities to be gainfully employed:
 - * The SGA level should be raised to at least \$720 per month level which is now permitted SSDI beneficiaries who are blind.
 - * The work incentive (1619) program should be extended to SSDI beneficiaries.
 - * Continuing outreach efforts should be made to expand the use of the 1619 program among SSI recipients with disabilities.
 - * Training and employment opportunities for AFDC recipients should be extended to people with disabilities, including essential supports and adaptations that enable them to benefit as fully as those without disabilities.
4. SSI eligibility determination for children with disabilities should be revised to require consideration of the individual child's functional limitations and require presumptive eligibility for children with certain genetic and congenital impairments that indicate a developmental disability.
5. Given the failure of optional SSP programs in most states to sufficiently complement the federal SSI payment in providing even minimal levels of income support, consideration should be given to new approaches to SSP such as:
 - * Updating and expanding federally-mandated SSP.
 - * Joint federal/state cost-sharing of SSP programs.

6. Efforts should continue to improve the efficiency of income support programs in ways that minimize the difficulties for program participants as well as for administrators.

MONTANA RECOMMENDATIONS

The primary source for Montana's recommendations is the Temple University Consumer Survey conducted by our state in 1989. Recommendations derived from the survey are followed by parenthetical reference to specific item numbers in the survey, indicating the percent of respondents dissatisfied with a particular service and the total number of respondents to that particular item. If the issue also arose during the public forums, that source is noted in the parenthetical reference as well.

1. Information regarding regulations for maximum allowable income and other specifications as they relate to SSI benefits must be more readily available and comprehensible (forums).
2. A method for filing the required court reports by representative payees needs to be developed which is not overly expensive (forums).
3. Need for increased assistance in area of financial management services assistance should be increased (Item 6.19: 31% of 13).
4. The Social Security Title II guidelines which define Substantial Gainful Activity (SGA) must be revised to encourage persons with disabilities to increase their work level. Currently the SGA is set at \$300.00 per month (forums).

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HOUSING

A VISION OF HOUSING FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

Having a home to call one's own is a basic goal for all Americans. A home is a haven, a place of comfort and safety that has been chosen by the individual or family as their "special place." Home is a place where things are arranged according to people's personal preferences and not the needs of a group; where people live with people with whom they have mutual attachments; and where they cannot be kicked out because they do not fit in. Children belong in their family home, whether biological, adoptive, or foster communities where individuals and families want to live, and household members should be in the home because they choose to be there, not "doubled up" with other family members because of shortages in housing, income, or supports. There should be a sufficient supply of decent, affordable housing so that people of all income levels have access to a home of their choice, including assistance in the rental and purchase of affordable housing as necessary. As a caring society, the nation will eliminate homelessness through a strategy focused on permanent housing options rather than temporary shelter, while enforcement of building and zoning regulations eliminates the use of substandard housing. The concept of safe, decent and affordable housing as a basic right will be revived and supported by a broad coalition of citizens, government, and the private sector.

People with developmental disabilities should live in the same kinds of homes as those without disabilities, with supports to the individual and adaptations of the living environment available as needed to enable them to live in non-segregated housing. Resources previously devoted to "residential service programs" must be restructured as resources for a flexible system of housing supports to individuals with developmental disabilities and their families that is based on the personal living goals and choices of each individual. The current system of "residential placements" should be replaced by a system of supports to individuals with developmental disabilities and their families in their own homes. Many types of supported living arrangements need to be available, including

individual units, group houses, apartments, and cooperatives, with options in the arrangements for live-in staff and the degree of "supervision" depending on the needs of the individual. Homes should be in areas without concentrations of people with disabilities and should provide meaningful opportunities for interaction with community members. Adults with developmental disabilities should be in a home of their choosing, including control over the selection of housemates; the home should be rented or owned by the individual. Children with developmental disabilities and their families should have the opportunity to grow up in a family home with foster family support. Members of communities and neighborhoods should be supported in efforts to welcome and interact with their neighbors and fellow citizens with developmental disabilities.

FACTS

* The Montana service system has for the last 20 years been resolutely committed to prevention of long term placement of children or other individuals with disabilities in large congregate facilities. The primary goal of Montana's Developmental Disabilities Division funding for these purposes is to prevent out-of-home placements or institutionalization for children. The Division, DDPAC, and the State's service providers have long recognized that large congregate facilities are not the most desirable living situation for anyone. They have gone to lengths to prevent admissions of individuals, and especially children to the state institutions for many years. Emphasis especially for children has been placed upon providing a continuum of services such as family training, case management, respite, and funding for therapies. This is provided in order that virtually every step has been taken to attempt to ensure that children remain in their own homes with their natural parents, or reside in foster homes in a normalized environment.

* As illustrated in Table 1, Montana funding allocations for congregate care facilities has remained static or even decreased from 1977 to 1988. However, for community-based services, State funding has increased by 231%, and combined state and federal financial

support has increased by 346%. In 1987, Montana ranked third in the country in the percentage of developmentally disabled persons receiving residential services in small community based settings (78%).

*** People with developmental disabilities who live in the community achieve greater levels of skill and independence than their counterparts who remain in institutions.** Studies of over 1,200 people with developmental disabilities who moved from large state institutions to community residences found significant gains in daily living skills (Larson and Lakin, 1989). None of these studies showed that people with developmental disabilities living in institutions did as well in developing skills as people living in the community. Research on "client" satisfaction and opportunities for independence and interaction with nondisabled community members also show greater gains for people with developmental disabilities living in the community (Horner, Stoner and Ferguson, 1988).

As illustrated in Table 13, 83% of the consumers surveyed residing in community-based group homes, and 82% of the consumers residing in supervised homes or apartments expressed satisfaction with their community living options. Of the individuals residing in substitute or foster placements, 100% expressed satisfaction.

*** Individuals with developmental disabilities, including people who are medically fragile, are able to live with families and in their own homes, so long as needed support is available.** For those in community living arrangements, average annual cost per resident varies much more by type of living arrangement (group home, apartment, or family home) than by the level of disability of the individual; these costs are generally lower than those for residents of large state institutions (Ashbaugh and Nerney, 1988).

In Montana in 1989, the average annual cost per individual residing in the state institution was \$59,894. The annual expense for an individual residing in an intensive group home was \$27,401. To provide intensive Specialized Family Care services developed with the express purpose of preventing children from placements into institutional settings,

the average annualized cost per child in 1989 was \$15,002 (Chisholm & Taylor, 1989). The Title XIX Medicaid waiver known as the Specialized Family Care (SFC) is discussed in more detail in the **Individual and Family Supports** chapter. The average annual cost per child receiving this service is deemed reasonable in relation to the costs per child in a group home or congregate care facility. Thus, the motivations for development of SFC waiver services which might have originally had philosophical basis in compassionate ideals of prevention of out-of-home placements of children have realized significant fiscal reinforcement as evidenced in the numbers above.

*** The single largest federal program that funds "housing" for people with developmental disabilities is the Medicaid program, primarily through the Intermediate Care Facilities for people with Mental Retardation and Related Conditions (ICF/MR) program:**

Eighty-eight percent of the institutional "placements" in the current developmental disability residential service system are financed by the ICF/MR program; only 25 percent of the community-based living arrangements are supported by the federal Medicaid program, including both the ICF/MR and Home and Community-Based Care Services Waiver (Lakin, Jaskulski, Hill et al., in press).

ICF/MR expenditures in FY 1987 reached \$5.6 billion; nearly 75 percent of these expenditures were for care in large state institutions.

*** There is a clear overall trend away from the use of large institutions and toward expanded use of community living options:**

The average size of facilities which serves as supervised residences for people with developmental disabilities has decreased from 22 in 1977 to 7.5 in 1987.

The total population of state institutions for people with mental retardation and other developmental disabilities decreased from an average daily population of 194,650 in 1967 to 151,532 in 1977 to 94,696 in 1987. Reduced admissions has been the most

significant factor in the reduction of state institution populations, even more than discharges to the community (Lakin, Jaskulski, Hill et al., in press).

The number of people with developmental disabilities living in smaller supervised residences (15 residents or fewer) nearly tripled between 1977 and 1987, from 40,433 to 118,570 or 46.3 percent of the total number of individuals in residential care units (White, Lakin, Sright et al., 1989).

* There has been a significant reduction in the use of out-of-home placements for children and youth with developmental disabilities approximately 48,500 were "placed" in 1987 compared to 91,000 in 1977. There is a particular decrease in the use of state mental retardation institutions for children and youth, from a total of 54,000 state institution residents 0 - 21 years in 1977 to only 12,024 in 1987 (Lakin, Jaskulski, Hill et al., in press).

* Many children with very severe disabilities and medical care needs, including children who are technology dependent (i.e., a child who requires constant or daily use of a medical device to compensate for the loss of a life-sustaining bodily function), are able to be cared for at home with their families. Research in six studies comparing actual home care costs with the costs of hospital care found savings with home care ranging from 42 percent to 99 percent (Burr, Guyer, Todres et al., 1983).

* Almost 52,000 people with mental retardation and related conditions currently reside in nursing homes (Braddock, Hemp, Fujiura et al., in press). Reviews of people with developmental disabilities living in nursing homes have found many who are neither elderly nor in need of nursing care, as well as a lack of habilitation and therapeutic services designed for people with developmental disabilities.

* A recent national survey found estimates of more than 60,000 people with mental retardation awaiting some type of residential option (Davis, 1987).

* There is a severe national shortage of housing that is affordable for people with low incomes. Many people with developmental disabilities have low incomes because of their dependence on income support programs that provide income at below the poverty level (e.g., SSI) or because their employment income is similarly at or below the poverty level.

In 1985 almost half (47.6 percent) of the households below the poverty line paid more than 50 percent of their income for rent; two-thirds of these households paid more than 70 percent (Scallet, Needleman, Jaskulski et al., in press).

An estimated half of the 4.5 million units of housing stock permanently removed between 1973 - 1983 were occupied by low-income households.

Over 300,000 federally-supported rental assistance units for low income households will be eligible for withdrawal from the program over the next five years.

* The combined factors of the shortage of affordable housing, increases in the overall poverty rate, and lack of community services/deinstitutionalization of people with mental illness are primarily responsible for the significant increase in homelessness over the past several years (Institute of Medicine, 1988).

Table 1 in Appendix B shows trends in expenditures by Montana's Developmental Disabilities Division. In fiscal year 1977 a total budget of \$5,725,000 was available to serve an initial 225 individuals in community settings. Federal sources provided 67% of the funds with the remaining 33% coming from State dollars. Currently, almost 2,400 individuals are receiving community-based services, at a budgeted cost during fiscal year 1989 of \$19,836,000. Federal dollars represent about 70% of the total budget with the remaining 30% coming from the State general fund. Figure 9 portrays the total number of individuals residing in various community placement arrangements from group homes to independent living situations. The handicapping conditions and age distribution of individuals residing in community placements are shown in Figure 10.

During the time period discussed previously - 1976 to 1988, expenditures for the Montana Developmental Center, as shown in Figure 27, show an overall change in funding of less than \$2 million, with significant decreases in spending during the period from 1977 to 1980. Table 1 in Appendix B illustrates that Montana's state general fund contribution to funding of congregate care facilities remained static with a slight decrease from 1977 to 1988.

* As we stress the importance of the individual's independence, it is equally important to attend to the level of independent capabilities which the individual possesses. As noted in Figures 28, 29, and 30, 55% of the consumer survey respondents indicate little or no general independence in their control and choice over their own lives, 58% indicated no choice in residence, and 64.3% indicated no choice in house or roommates. Figures 31 and 32 however, demonstrate that fully 75% of the respondents need a lot of assistance to live on their own in the first place, and 66% of the adults and 87% of the children responding to the surveys need considerable assistance to care for themselves.

Nevertheless, it is vital that service systems provide as many opportunities as possible for individuals to choose their living circumstances to the fullest extent conceivable, for as Figures 33 and 34 illustrate, independence and integration are highly salient qualities of life for this group of respondents.

The ICF/MR Program: The ICF/MR program is an optional service under the Medicaid program. It is now available in all states and the District of Columbia. Growth in the cost of the ICF/MR program is primarily responsible for the major increase in Medicaid-funded long-term care expenditures over the past decade (DHHS, 1987).

(1) Expenditures

Total expenditures for the ICF/MR program (federal and state) have increased from a total of \$1.1 billion in FY 1977 to \$5.6 billion in FY 1987. During this period annual expenditures per ICF/MR resident increased from \$10,000 to \$37,600. ICF/MR services are particularly expensive in large state institutions: \$54,516 per

resident in FY 1987, compared to an average Medicaid expenditure of a little over \$15,000 per person for people served through the Home and Community-Based Care Waiver program. 86 percent of the ICF/MR expenditures in FY 1987 were for 24-hour care in large facilities (16 or more persons); 72 percent were for care in large state institutions.

(2) Total Number Served

The ICF/MR program serves a relatively small number of people: 144,350 in FY 1987 nationwide, including both public and private facilities. In most states the number of ICF/MR residents decreased between 1982 and 1987 because of the reduced use of state institutions. The national total was up only 2.6 percent during this period, reflecting the increased use of the program in some states.

(3) Number and Size of ICF/MR Facilities

There has been a significant growth in the number of small ICF/MR facilities (4 to 15 residents), from 1,202 facilities with 9,714 residents in 1982 to 3,098 facilities with 23,528 residents in 1987. Despite the increases, however, only 16 percent of all ICF/MR residents are in these smaller facilities. The average small ICF/MR serves 7.6 residents; under federal legislation authorizing the ICF/MR facilities (16 or more residents) serving almost 121,000 people in 1987. The average large ICF/MR serves 148 people.

(4) State Institutions

States rely heavily on the ICF/MR program to fund their state institutions for people with mental retardation/developmental disabilities. In 1987, the care for 93 percent of all state institution residents was financed by the ICF/MR program. At the same time the total number of state institution residents continues to decline in virtually all states, and 20 state institutions were closed or are scheduled to close between 1987 and 1990. State institutions funded by the ICF/MR program are generally the largest of all ICF/MR facilities, with an average size of 322.7 residents.

Over 60 percent of all ICF/MR residents are in these large state institutions, supported by 72 percent of all ICF/MR expenditures.

Montana's primary ICF/MR facility, Montana Developmental Center currently provides care, treatment, training, education and necessary medical treatment for approximately 185 persons with mental retardation. On July 1, 1970 the population at MDC stood at 865 persons with Developmental Disabilities. At that time, a nine year plan of resident placement was developed, with the goal for 1979 of a reduction of 665 individuals to a target population of 200. That goal was met prior to the 1979 deadline, and the population remained relatively stable during the decade of the 1980's (Figure 1 in Appendix A).

As an ICF/MR facility, MDC participates fully in the Medicaid reimbursement program; nearly all of its residents are Medicaid eligible. From 1977 to the present the ratio of federal to state funding to support the facility has changed significantly. In 1977, State funding represented 75% of the total costs, with Medicaid funds providing the other 25%. By 1988, Medicaid funds constituted 57% of the total cost for maintaining the facility versus 43% provided by the State.

Table 1 in Appendix B provides more detail regarding sources of funding for both institutional and community-based services for Montana's developmentally disabled population. As illustrated in the table, while the State funding allocations for the congregate care facilities has remained static or even decreased from 1977 to 1988. However, for community-based services, State funding has increased by 231%, and combined state and federal financial support has increased by 346%. In 1987, Montana ranked third in the country in the percentage of developmentally disabled persons receiving residential services in small community based settings (78%)(Montana Interagency Task Force, 1989).

(5) ICF/MR Resident Characteristics

Although many individuals with severe and challenging disabilities live in small community-based ICF/MR facilities, the residents of these units generally have less

severe disabilities than the residents of large state ICF/MR institutions. ICF/MR residents also tend to have more severe disabilities than the residents of facilities that are not ICF/MR certified. Although federal ICF/MR regulations permit use of the program for people with mental retardation and "related conditions," the overwhelming majority of ICF/MR residents are people with mental retardation. Only 0.6 percent of the ICF/MR residents nationwide are reported to have epilepsy, cerebral palsy, autism or spina bifida without also being indicated as having mental retardation, although the residents with mental retardation include some people with so-called "borderline" retardation (Lakin, Jaskulski, Hill et al., in press).

Figure 35 illustrates the distribution of levels of mental retardation, age and ethnic origin for individuals residing in Montana's largest state institution, MDC. The majority (72.6%) of MDC residents fall in the severe/profound range of retardation with the next largest group (18.8%) falling in the moderate range of retardation.

As discussed in the Context for Services section, the definition of developmental disabilities used by the Division varies from the federal definition, which at this time is used only by the agencies funded under P.L. 100-146.

The state of Montana does not specifically follow the federal definition in determining eligibility for developmental disabilities services. Please refer to the Context section for further discussion.

The Home and Community Based (HCB) Waiver Program: The HCB waiver program was authorized in 1981 as an alternative approach to the use of Medicaid financing for long-term care in ICF/MR facilities and nursing homes. It is an optional program and requires federal approval of the waiver application. Initial waivers are for three years, with renewals approved for a five-year period. People with developmental disabilities may be served through the waiver if they would otherwise require ICF/MR (or in some

cases nursing home) services funded by Medicaid, so long as Medicaid costs are less than would have been incurred without the waiver. The program has expanded rapidly, with 40 states now participating or applying. Expenditures for waivers serving people with developmental disabilities have grown from \$2.2 million in FY 1982 to over \$441 million in FY 1988 (Braddock, Hemp, Fujiura et al., in press).

The services most commonly covered by HCB waiver plans include case management, residential services, habilitation, transportation, respite, homemaker, and adult day programs (Clinkscale and Ray, 1987). Waivers cannot be used to fund "room and board" costs. They can be used, however, to fund services provided within residential care programs as well as to fund supports to individuals and families living at home. A recent study of seven HCB waiver states found that six are using the waiver primarily as an adjunct to their residential service system. Among the six the proportion of waiver beneficiaries in supervised residential placements ranged from 67 to 100 percent (Lakin, Jaskulski, Hill et al., in press). Room and board for HCB Waiver clients in residential service programs is generally funded with income maintenance programs such as SSI, state SSI supplement programs, and SSDI.

The total number of HCB waiver beneficiaries reached 29,087 in FY 1988, up from 20,256 in FY 1985. Surveys of state officials have indicated that the major strength of the waiver is the ability to design services to meet the needs of individuals and its flexibility in contrast to the facility-based services of the ICF/MR program; the waiver has been credited by many states in the reduction of more expensive and restrictive ICF/MR utilization (Lakin, Jaskulski, Hill et al., in press).

Carrying the concept of avoidance of out-of-home placement for children as far as possible, in 1983 Montana's state legislature Title XIX Medicaid waiver Specialized Family Care (SFC) program. In 1984, approximately 35 children and families were provided with services. In September, 1989, 101 children, 10% of the total children receiving services from the Division, were enrolled in the program, with 5.7% of the Division budget

committed for services. See the Context of Services section for further discussion regarding SFC services.

Model Waivers: The so-called "model" waiver program is sometimes also referred to as the "Katie Beckett" waiver because of its evolution from the earlier waivers for individual children with serious health care conditions. Options for states are the same as for the HCB waiver as to flexibility in services covered and focus on prevention of Medicaid-funded institutional care. The maximum number that can be served through a model waiver, however, is limited to 200 per state. Many model waivers are used to permit children with severe disabilities and challenging medical conditions to be eligible for Medicaid-funded services in the home (and in medical care facilities, as needed) who would otherwise only be eligible for Medicaid if they were in an out-of-home placement because of their family income and resources. As of August 1988, 23 states were using model waivers of various size and target populations, including 11 waivers for people who are elderly or have a disability; 4 for people with mental retardation and other developmental disabilities; and 8 for children with disabilities. An estimated 359 people with developmental disabilities were served in FY 1988 with expenditures of \$5.26 million.

Medicaid Eligibility for Children with Disabilities: The Tax Equity and Fiscal Responsibility Act (TEFRA) of 1987 gave states the option of extending Medicaid categorical eligibility to children and youth with disabilities living at home who meet level of care requirements for institutionalization and who would be eligible for Medicaid if they lived in an institution. Children served through the TEFRA option are entitled to the state's basic Medicaid services; the state cannot add services targeted specifically to children with disabilities as can be done under the HCB or model waiver provisions. Unlike the waivers, however, this option extends Medicaid benefits to all children with disabilities who meet the eligibility requirements; waivers can be (and are) limited to people with certain kinds of disabilities and, in some cases, only to residents of a certain

geographic area. As of April 1989, 22 states had added the "TEFRA" option, up from only three states in July 1987.

Nursing Homes: The Medicaid program funds nursing home care for people who require nursing care at either the skilled or intermediate care level. Separate standards and certification for skilled nursing facilities and intermediate care facilities has recently been consolidated; beginning in October 1989 there will be a single federal "nursing home" certification. Medicaid is the single largest funding source of nursing home care, approximately \$13.6 billion in FY 1987. (Medicare financing is limited to the coverage of short nursing home stays that have been immediately preceded by hospitalization.) Over 88 percent of all nursing home residents are age 65 or older, while only 32 percent of the nursing home residents with mental retardation are over age 65 (Lakin, Jaskulski, Hill et al., in press).

Concerns about the inappropriate use of nursing homes were a major factor in recent nursing home reform legislation (Omnibus Budget Reconciliation Act of 1987/P.L. 100-203). These concerns included the use of nursing homes for non-elderly people with developmental disabilities and for people who do not need the level of medical care provided by a nursing home; and people who are not receiving the habilitation and therapies they need. The new legislation requires that all nursing home residents with developmental disabilities must be determined to require the high level of medical/nursing services offered and must also receive individually defined "active treatment." Current nursing home residents with developmental disabilities who are not in need of nursing services must be moved to a more appropriate setting unless they have lived there. Those who remain must be provided with active treatment. States that have not already done so must also initiate screening procedures to avoid future inappropriate placement of people with developmental disabilities into nursing homes.

In response to the requirements of the Federal Social Security Act, as amended by the Omnibus Budget Reconciliation Act (OBRA) passed by Congress in 1987, beginning

in the Fall, 1989, the Economic Assistance Division (EAD) and the Developmental Disabilities Division (DDD) implemented Level I and Level II reviews of clients residing in nursing homes throughout the State. Subparagraph(C) requires that states determine and meet the active treatment needs of current nursing facility residents, either inside the facility or in newly developed alternative services.

In October 1988, the EAD and DDD identified a total of 306 individuals who appear to have Mental Retardation or a related condition. Level I and Level II screening processes are expected to be completed by April 1990. EAD directly administers the Medicaid program in Montana, and is responsible for ensuring provision of "active treatment services" to those individuals who need such services and choose to continue to remain in nursing facilities. DDD is responsible for developing and administering the alternative community-based services required by those who will no longer reside in nursing facilities.

Following the Level II screenings, EAD and DDD will develop and propose plans to meet the active treatment and other service needs of current nursing facility residents with Mental Retardation. At the present time it is impossible to identify the specific type and number of services that will be contained in the plans. It is expected that any necessary alternative services will be community-based and include both small ICF/MR and Medicaid Waiver services. Funding will be requested from both the federal and state government in order to provide the services necessary. A request for funding will be submitted by SRS to the Governor for consideration in the executive budget development process, with final consideration and approval coming from the 1991 Montana Legislature. HCFA and HCBS Waiver requests will be developed and submitted for approval to Medicaid funding sources.

Pending approval of state and federal funding mechanisms, by approximately June, 1993, DDD and EAD activities will be completed providing active treatment and other service needs for the identified population. Those activities will include development of

alternative residences, movement of individuals that choose to reside in those settings, and development of appropriate active treatment services in nursing home settings.

HUD Section 202 Direct Loan Program: The Department of Housing and Urban Development (HUD) administers the Section 202 program, a Federal Direct Loan Program to non-profit organizations to support the development (both new construction and rehabilitation) of rental units to meet the special housing and related needs of non elderly handicapped individuals and families. The loan program is coupled with a related rental assistance program that provides funding to pay the difference between the tenant's rental payment (set at 30 percent of tenant income) and the total amount of the Section 202/Section 8 (rental assistance) program to better meet the specialized needs of non-elderly people with disabilities, in particular by increased emphasis on supportive services and less orientation to large congregate care. People with developmental disabilities are specifically designated as eligible populations for housing funded through the new 202 program for "non-elderly handicapped families" authorized by the Housing and Community Development Act of 1987. Information of FY 1989 loans awarded through this program is not available.

Prior to enactment of the new 202 program for non-elderly people with disabilities, some housing for individuals with developmental disabilities was financed through the regular 202 program. This program finances loans to non-profit organizations for the construction or rehabilitation and management of rental and cooperative congregate housing for elderly persons and people with disabilities. The Housing Act Amendments of 1978 specified that these funds were to be used to serve the unique needs of individuals with disabilities ("handicaps") between the ages of 18 and 62 or families which include an individual(s) of any age with a disability, including services and opportunities for optimal independent living, participation in normal daily activities, and community integration. Federal guidelines in relation to housing costs and available loan amounts have made it difficult to obtain approval for anything smaller than a 12-person unit. The FY 1988

federal allocation for this program was \$234.5 million, estimated to provide housing for 5,221 non-elderly people with disabilities. Based on HUD's categories, the loans will provide housing for 1,621 individuals with mental retardation and other developmental disabilities; 1,859 people with physical disabilities; and 1,741 people with chronic mental illness. The average size of these facilities will be 18.7 residents.

Federal funding for the 202 program, and therefore the number of projects, has been reduced significantly, from a high of 30,000 projects in FY 1976 to a low of 10,300 in FY 1989. The average time from loan application approval to occupancy of the housing by people with developmental disabilities is three to four years.

Rental Assistance: The Section 8 rental assistance program provides payments to owners of rental housing to subsidize the contribution of low-income families, individuals with disabilities and elderly, to increase their rent-paying capacity. Housing providers may be either private owners or local public housing authorities. Although replaced by the Section 8 Voucher Program in 1983, existing 15-year Section 8 certificates continue until their expiration date. Section 8 certificates issued in conjunction with a particular project funded by a Section 202 loan for congregate housing for people who are elderly or have disabilities may be used only for the specific 202 project. "Regular" Section 8 certificate, now replaced by the voucher program were issued to the low-income individual or family and could be used in renting accommodations selected by the tenant, provided that the total rent was within HUD Fair Market Rent limits for the geographic area. There are also limits to the number of Section 8 certificates issued in each area; however, these limits do not apply to those used in renting Section 202 funded units. The Section 8 Voucher Program, also known as the Modified Section 8 Existing Housing Certificate Program, provides payments to participation owners of rental housing stock. The primary difference between the voucher program and the rent subsidy program is that the tenant contribution varies depending on the rent negotiated between the low income tenant and landlord; rents may exceed the official "fair market value", with the tenant paying the difference. Under the

rent subsidy program, rents cannot exceed the federally determined fair market value for the type of housing and geographical area, and tenant payments are limited to 30 percent of their available income. The supply of Section 8 certificates in many areas is far less than the number of requests. Because low income rental assistance is not an entitlement, subsidies are available only to the extent that federal funds are available. In 1985, for example, less than one-quarter of the nation's poorest families in rental housing were receiving such assistance (Carliner, 1987.)

Federal Housing Assistance In Rural Areas: The Farmers Home Administration of the U.S. Department of Agriculture administers the federal housing assistance programs targeted to low income residents of rural areas and loans for the development of housing for residents of rural areas with disabilities. The Rural Rental Assistance Payments (Section 521) program provides rental subsidies through contracts with rural housing sponsors, with the same goals, target populations, and eligibility requirements in relation to disabilities as the HUD Section 8 program. The Rural Housing for Persons Who Are Elderly or Have Handicaps (Section 515) program provides loans for the purchase, construction, improvement or repair of rental or cooperative housing for rural area residents who are elderly or have handicaps, comparable to the Section 202 program. Unlike the HUD 202 program, which may be used for the construction of ICF/MR facilities, it may not be used for nursing homes, "special care" facilities, or institutional-type homes.

McKinney Act Assistance to the Homeless: A variety of federal programs were authorized by the Stewart B. McKinney Homeless Assistance Act Amendments of 1988 (P.L. 100-628), primarily providing federal grants to the states and Puerto Rico to assist them in meeting the current needs of homeless individuals and families, decreasing the number of homeless, and preventing future homelessness. Special emphasis is to be placed on housing for elderly persons, people with "handicaps", families with children, Native

Americans, and veterans. Stop gap programs include an emergency food and shelter program and grants for temporary shelter for people who are homeless. There is also a Supportive Housing Demonstration Program administered by the Department of Housing and Urban Development which funds transitional and permanent housing demonstration grants. These projects include supportive housing arrangements targeted to deinstitutionalized homeless individuals, homeless people with mental disabilities and other people with handicaps; people with disabilities who are at risk of being room occupancy dwellings, which is used by many people with disabilities in urban areas. Permanent housing ("group home") units funded through the McKinney Act may not serve more than eight homeless people with disabilities.

In FY 1988 HUD awarded \$3.6 million in grants to 41 projects nationwide to develop permanent housing for homeless people with disabilities. Several are targeted to people with developmental disabilities. An additional \$24.6 million appropriated for permanent housing grants was not expended due to a lack of applications meeting program requirements and was reallocated to the transitional housing grant program, as required by federal legislation. \$15 million for permanent housing grants, including grants for housing for people with disabilities who are homeless or at risk of being homeless, is available in FY 1989.

The McKinney Act programs also include a block grant to states to reduce and prevent homelessness among people with serious mental illness, with emphasis on the provision of mental health and related services (i.e., to be complementary to the other programs which are expected to fund the actual housing.) This program is discussed further in the chapter on Individual and Family Supports.

The Fair Housing Amendments Act of 1988: These landmark amendments represent the first time that people with disabilities have been brought under the protection of the federal fair housing statute. The act makes it unlawful to discriminate "in the sale or rental, or otherwise make unavailable or deny, a dwelling to any buyer or renter" in

relation to the handicap of the individual or the intended use of the property as a home for people with disabilities. (For a full discussion of this Act, please see the chapter on Civil Rights).

Child Welfare Services, Adoption and Foster Care: The federal government provides assistance to the states to support adoption assistance, including supplementary funding to families who adopt children with disabilities; quality foster care; and services to families at risk of breakup which are designed to prevent the excessive use of foster care. These programs are discussed in the chapter on Individual and Family Supports.

Centers for Independent Living: Federal grants are made to states and to individual independent living centers (ILCs) to support programs designed to promote independence, productivity and community integration for people with severe disabilities. 20 percent of the ILCs sponsor transitional housing arrangements and 15 percent provide permanent housing. Additional information on the federal independent living program is included in the chapter on Individual and Family Supports.

CRITICAL ISSUES

- * The approach to housing for people with developmental disabilities needs a "paradigm shift" from residential services to supported housing so that people are living in their own homes rather than being "placed" in a residential care facility.
- * There is a corresponding need to shift resources from institutional and facility-based care to individual and family supports that are tailored to the needs and wishes of the individual with developmental disabilities.
- * There is a lack of alternatives to funding housing for people with developmental disabilities through the medical care system, despite the general inappropriateness of the medical care model.

Social Changes/Demographic Issues

- * There is a national crisis in the availability of affordable housing, especially for those with the lowest income levels. The rapid growth in homelessness throughout the 1980's has affected many people with disabilities and their families. They are especially vulnerable because of their low income status and, in some cases, because of discrimination and other factors associated with the disability itself.
- * There is a renewed national interest in support and preservation of "the family", even as major changes in social mores have redefined the family to include many single-parent families and other arrangements as part of the mainstream. Meaningful efforts to help strengthen and support families, however, have not been developed to correspond to the "pro-family" rhetoric. Families with children are the fastest-growing segment of the homeless population.

Policy Issues: Programmatic

- * The primary emphasis is still on facility-based residential care, in particular the use of large congregate facilities and institutions, especially in federally-supported programs. The major exception, the Supplemental Security Income (SSI) program, provides benefits well below the poverty line, where the shortage of affordable housing is the most acute.
- * The lack of available support and residential alternatives continues to force people with developmental disabilities into inappropriate and unnecessary residential placements. Without considering the impact of revisions of the Montana definition of developmental disabilities, the number of persons waiting for services in the State has risen from 364 in July of 1980 to 1066 in December of 1988. The 1988 figure represents 439 (41%) individuals currently receiving no services and 627 enrolled in developmental disabilities services but identified as in need of more appropriate services. This growth in waiting lists has occurred despite the fact that Montana has continually and significantly upgraded and expanded the level and scope of services it provides, with an approximate 62% increase in the number of persons receiving services in Montana over the last 10 years (1980-1989).

- * The medically-oriented, congregate long term care model of the ICF/MR program is inappropriate for most people with developmental disabilities; even when the level of care is technically appropriate, the ICF/MR model is extremely difficult to use in ways that promote independence, productivity and community integration because of its medical care facility orientation.
- * The Home and Community-Based (HCB) services waiver cannot be used to provide individually-oriented services to all who need them because total costs of individual waivers cannot exceed the Medicaid funds that would have been expended had these people been in an ICF/MR, and states must document that those being served would otherwise have been institutionalized. In addition, waiver support is potentially unstable because it is a federal demonstration program, is applied for at state option, and because individual waivers are time-limited.

Policy Issues: Rights/Access

- * Many people with developmental disabilities do not get to choose their home and their housemates, but instead are "placed" in a residential care facility.
- * The new Fair Housing Amendments are significant, but much remains to be done in assuring access and non-discrimination on the basis of disability. (Please see chapter on Rights).
- * Despite the broad-based support for family homes for children with developmental disabilities, there are major gaps in the systems of care for children who are medically fragile and/or technology dependent. These children have minimal access to home-based care and other "least restrictive environment" alternatives.
- * Significant numbers of incidents involving physical and sexual abuse of board and care residents and neglect of residents' medical needs are taking place; many residents of board and care facilities are people with developmental disabilities.

Policy Issues: Fiscal/Resource

- * Federal resources that can be used to support housing, modify environments and promote independent living are minimal, especially when compared to the \$5.6 billion (approximately 52 percent federal/48 percent state funds) being expended on the ICF/MR program. New findings on the cost-effectiveness of non-institutional alternatives, in particular the individual housing support models, have not been translated into fiscal policies.
- * There is much more demand for housing supports and residential alternatives than there are funds available. Most states have extensive waiting lists for homes in the community.
- * The impact of the new ICF/MR standards and the implementation of P.L. 100-203, requiring relocation of several thousand people with developmental disabilities currently inappropriately housed in nursing homes, is unknown. If resources are increased to expand/improve institutions rather than to use the HCB waiver and other supported housing alternatives, it will significantly erode further the availability of resources for community service development.
- * The infusion of resources through the McKinney Act is helpful, but woefully inadequate in comparison to the need for more support for the development of low income housing.

Policy Issues: Data/Monitoring/Accountability

- * Individuals with developmental disabilities and their family members are frequently ignored in the monitoring process, rather than empowered. The wishes and plans of the person with developmental disabilities are all too often considered peripheral to monitoring, rather than its heart.
- * There are major unresolved questions about the principles that should be observed in monitoring places where people with developmental disabilities live and the services received there, including federal vs. state and local standards; separation of responsibility

between monitoring and provider status; and the difficulties of using nursing home oriented monitoring procedures, as with the ICF/MR program.

- * There is a lack of data on residents with developmental disabilities in board and care facilities, as well as widespread difficulties in the monitoring of conditions in board and care units, especially those that are unlicensed.

- * State of Montana Department of Family Services staff license the approximately 90 group homes throughout the state as a small part of their overall licensing responsibilities. The limitations on staff allow them to make only one announced visit per year to each home. Current resources for this function are inadequate, thus providing insufficient time for visits to homes and the lack of possibilities for unannounced visits to assure continued compliance. Follow-up visits do occur when a complaint is filed by DDD field staff, relatives, neighbors, or other concerned individuals.

Public Attitudes

- * The "not in my backyard" (NIMBY) syndrome continues to reduce opportunities for housing for people with developmental disabilities in some neighborhoods and communities. New federal Fair Housing Amendments, however, considers this discrimination and therefore actionable.

- * There is widespread ignorance among community members as well as policy-makers outside the field of developmental disabilities of the overwhelming evidence that people who live in the community have much greater gains in independence, productivity and integration than their counterparts in the institution. There is a comparable level of ignorance about the proven ability of people with severe disabilities, people who are technology-dependent, and people with challenging behaviors to live in homes in the community and to be integrated with people who are without visible disabilities.

- * The availability of a "free and appropriate" public school education for children with disabilities has been a significant factor in the reduction of institutional admissions. The overwhelming majority of people with developmental disabilities and their families expect

community living opportunities, including continuing opportunities to interact with people without a disability.

NADDC RECOMMENDATIONS

1. Housing policy goals for people with developmental disabilities should be redefined to:
 - * Focus on supports, environmental adaptations, and housing characteristics selected by the individual and tailored to individual needs;
 - * Empower individual adults to own or rent their own homes; and
 - * Ensure that children live in a family home.
2. Funding sources should be realigned to focus on resources to individuals rather than facilities; funding for housing should not be based on a medical care model.
3. The federal commitment to ensure the availability of decent, affordable housing must be reasserted and acted upon, such as the bipartisan-supported National Affordable Housing Act recently introduced (S. 565/566).
4. The implementation of the new ICF/MR regulations and P.L. 100-203 (nursing home reforms) should be carried out in ways that promote the use of community alternatives rather than increased resources dedicated to institutions.
5. National attention must be given to problems of neglect and abuse in board and care homes, such as consideration of the proposals to improve state monitoring of these facilities included in the National Board and Care Reform Act of 1989 (H.R. 2219).

MONTANA RECOMMENDATIONS

The primary source for Montana's recommendations is the Temple University Consumer Survey conducted by our state in 1989. Recommendations derived from the survey are followed by parenthetical reference to specific item numbers in the survey, indicating the percent of respondents dissatisfied with a particular service and the total

number of respondents to that particular item. If the issue also arose during the public forums, that source is noted in the parenthetical reference as well.

1. More residential services must be developed for persons with disabilities, with some of them designated for specific groups of persons with disabilities (e.g., Prader-willi syndrome, children, elderly persons) (forums).
2. Attention should be given to dissatisfactions expressed by persons residing in group homes to determine the source of their difficulties (Item 2.7: 16.7% of 18).
3. Supervised independent living arrangements need to become increasingly available as more persons with disabilities become capable of residing in those settings (Item 2.9: 18.2% of 11).
4. Homemaking assistance and training needs to be increased (Item 2.12: 28.6% of 7).
5. Housing subsidies (e.g., section 8) need to be increasingly available and procedures for acquiring them need to be more manageable (Item 2.13: 60% of 5).
6. Residential services should to be more individualized to the specific needs of persons with disabilities rather than making them match the services offered (forums).
7. Service providers in residential facilities must receive higher quality training and sufficient pay to reduce staff turnover and assure that clients receive capable and competent services (forums).
8. Residential staffing in group homes should be sufficiently flexible to accomodate elderly persons with disabilities remaining at home on "retirement" status instead of being required to spend their days at a day program (forums).

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APPENDIX F

FIGURES AND TABLES

Level of Satisfaction with Services - Housing

<u>Service</u>	Percentage of Participants Receiving <u>Services</u>	% Satisfied of those Receiving <u>Services</u>	% Dissat. of those Receiving <u>Services</u>
<u>Residential Services</u>			
Group Home or Apartment (6-9)	18%	83%	5%
Supervised Home or Apartment	11%	82%	27%

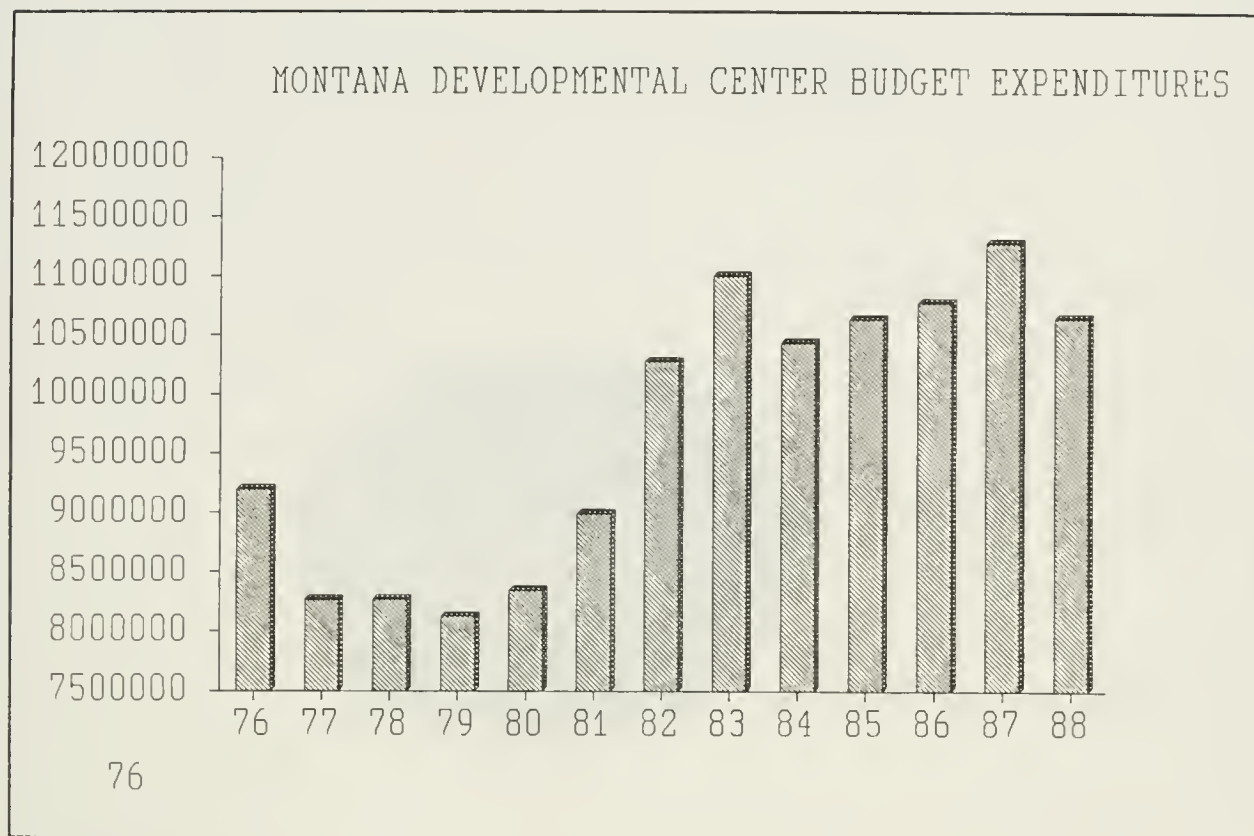
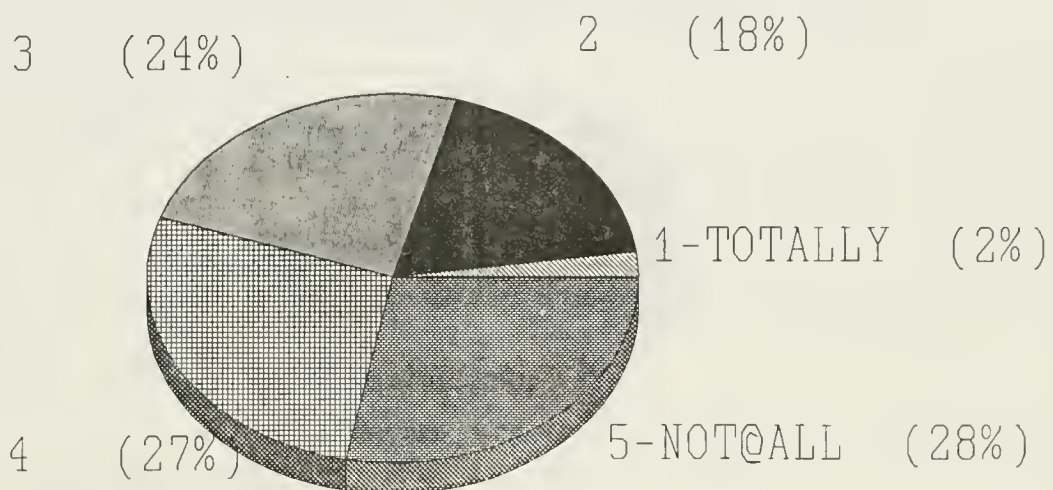


FIGURE 27

DEGREE OF INDEPENDENCE

**FIGURE 28**

Consumer Survey 1989

CHOICE OF RESIDENCE

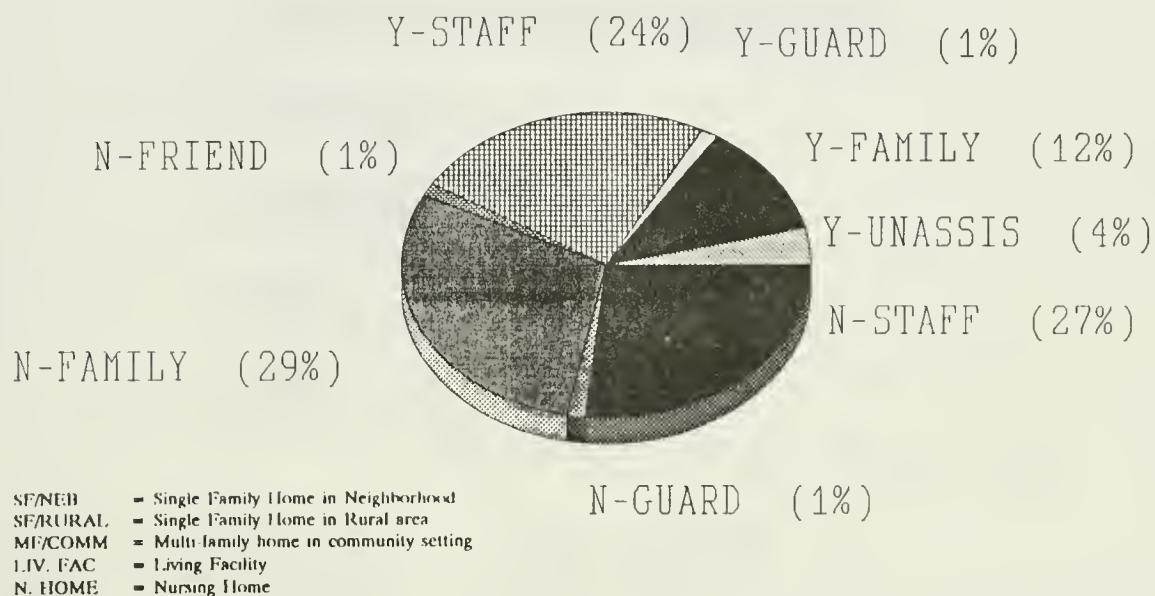


FIGURE 29

Consumer Survey 1989

CHOICE OF HOUSEMATE/ROOMMATE(S)

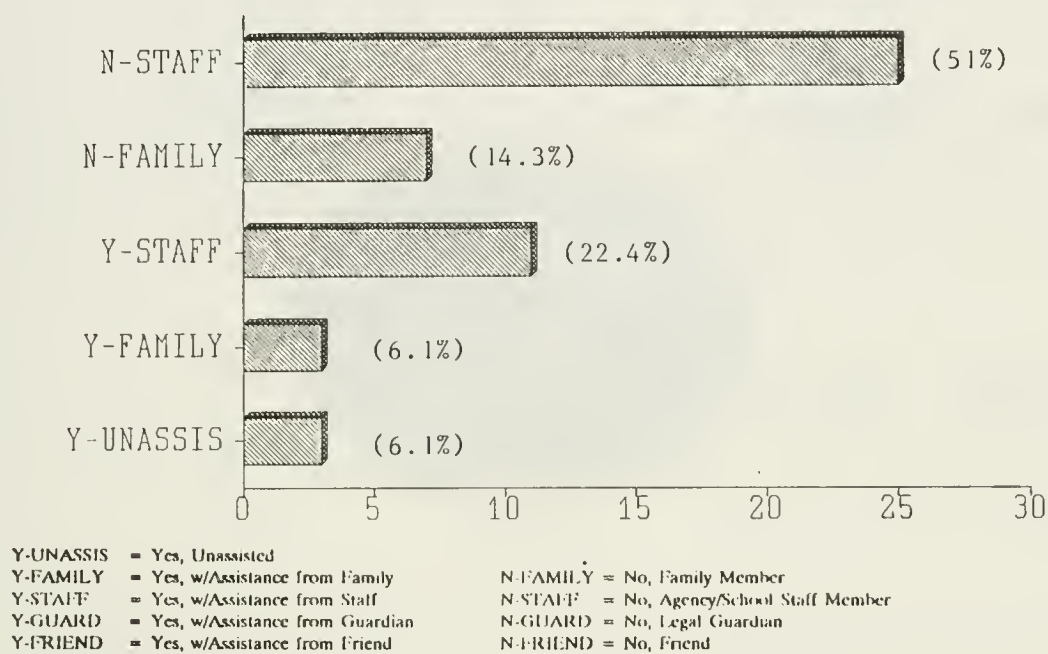


FIGURE 30

Consumer Survey 1989

DEGREE OF ASSISTANCE NEEDED TO LIVE ON YOUR OWN

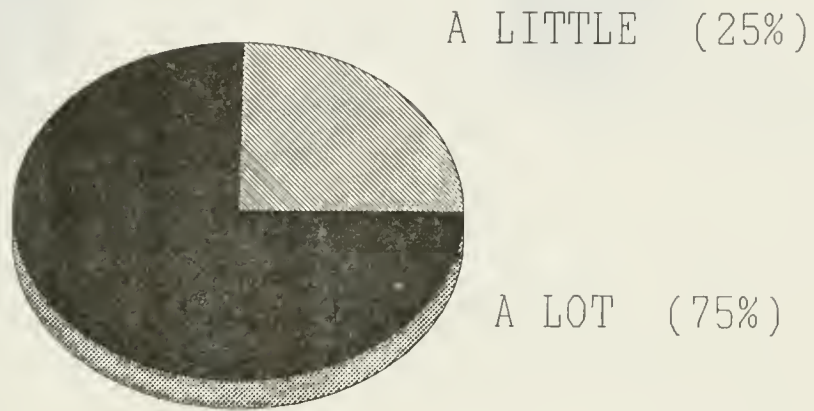


FIGURE 31
Consumer Survey 1989

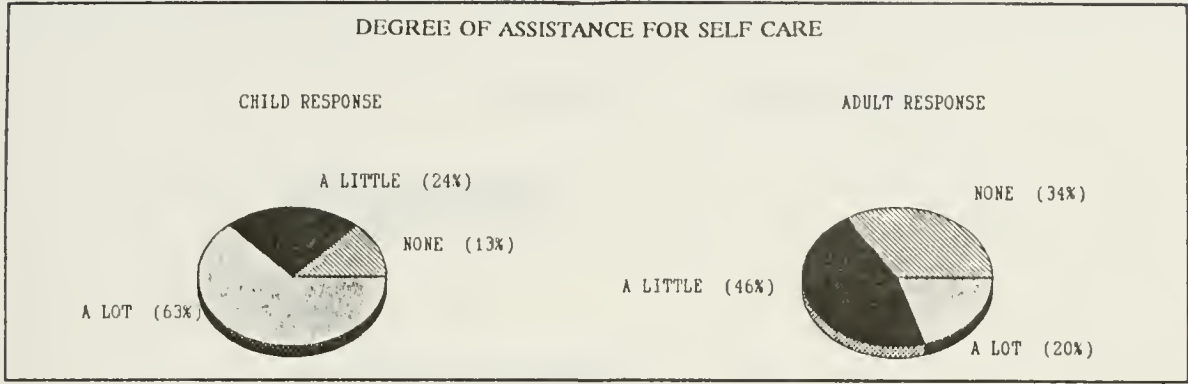


FIGURE 32
Consumer Survey 1989

IMPORTANCE OF INDEPENDENCE

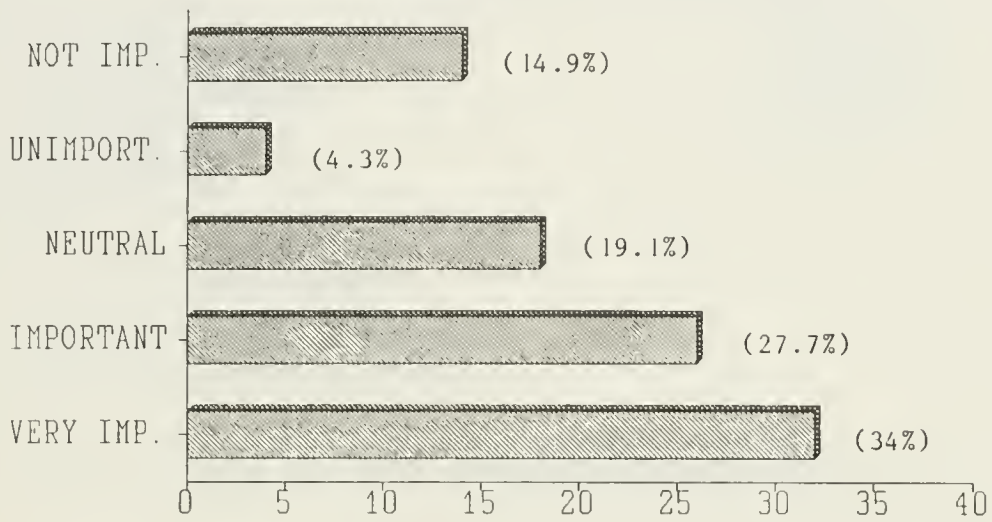


FIGURE 33
Consumer Survey 1989

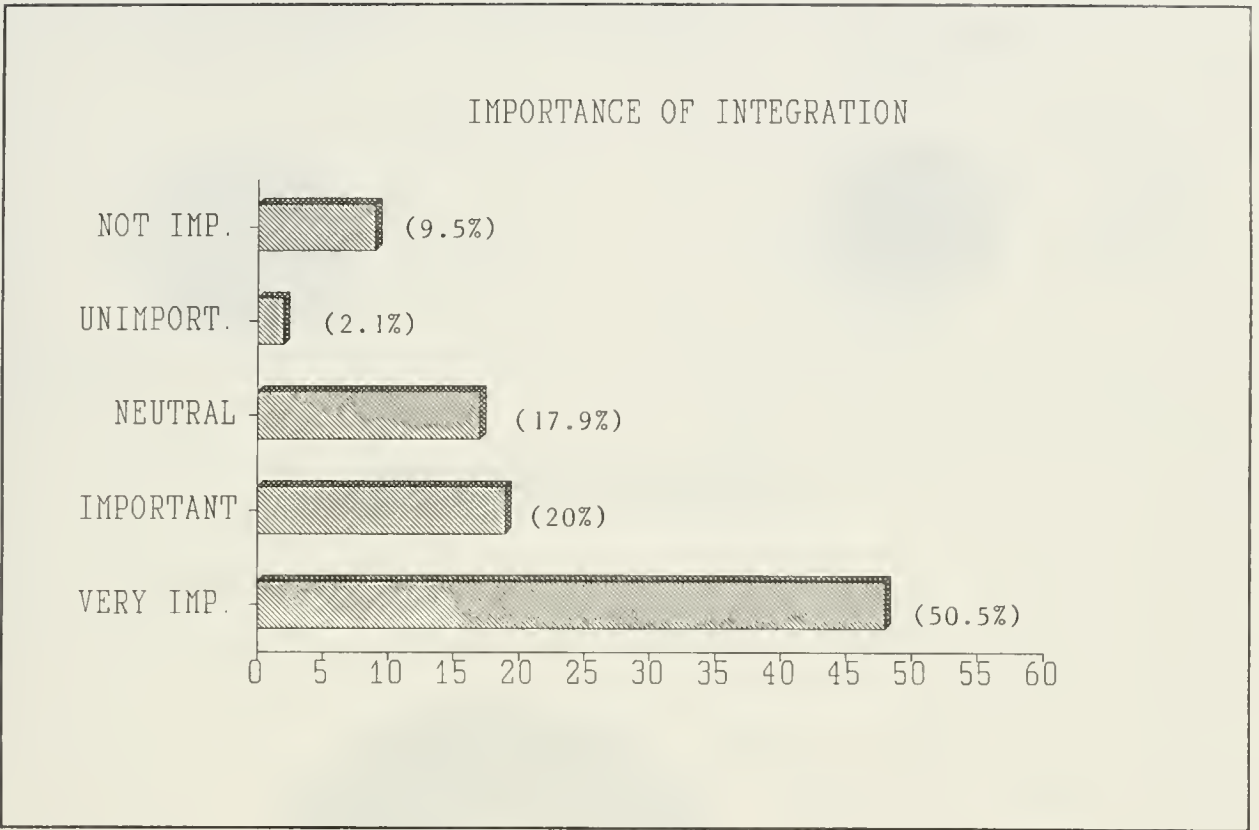


FIGURE 34
Consumer Survey 1989

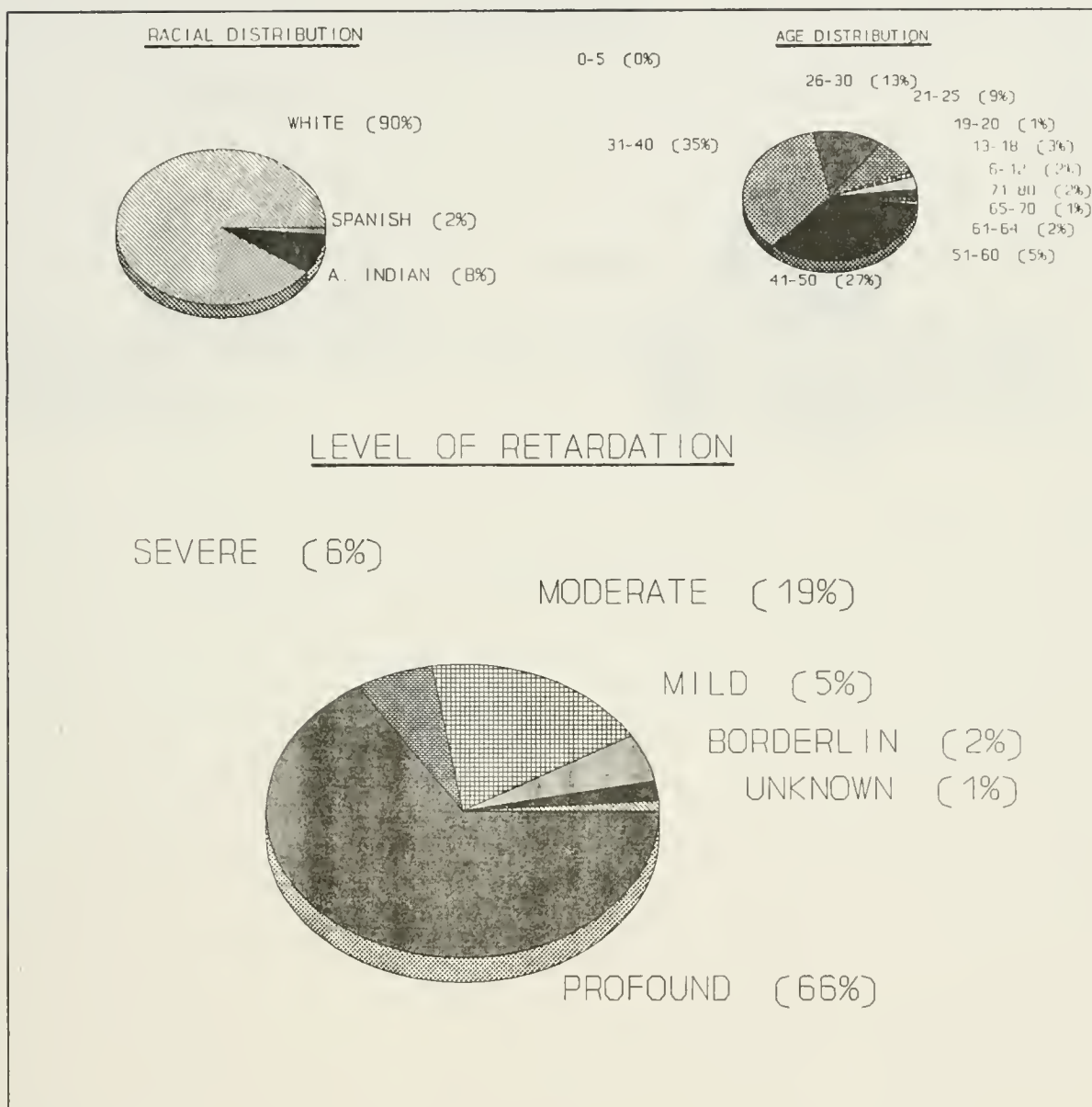
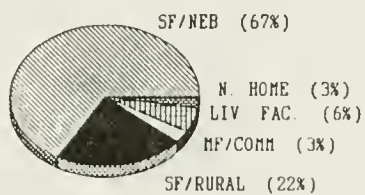


FIGURE 35
MDC, Dec. 1989

RESIDENTIAL SETTING

CHILD RESPONSE



ADULT RESPONSE

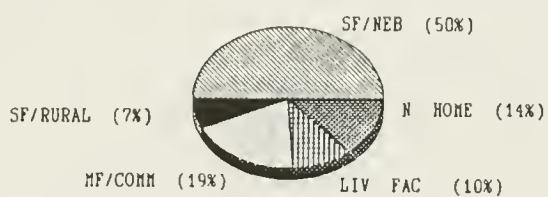
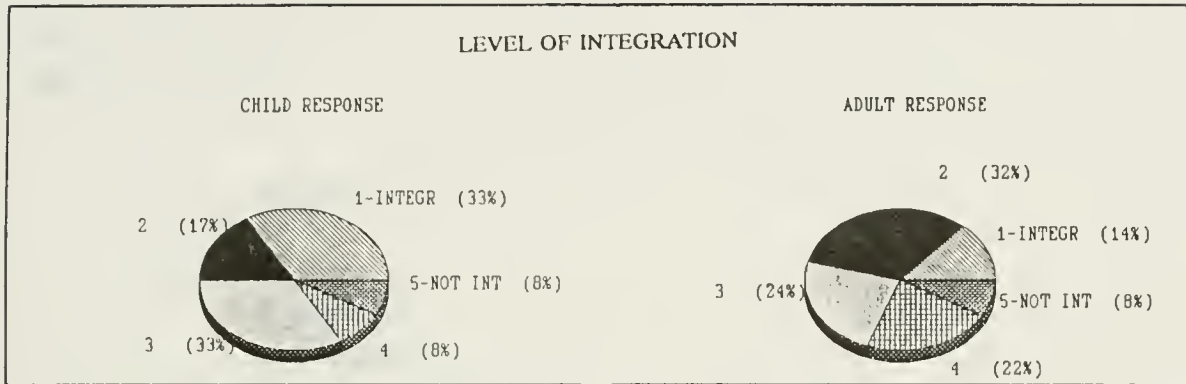


FIGURE 36

Consumer Survey 1989

SF/NEB = Single Family Home in Neighborhood
 SF/RURAL = Single Family Home in Rural area
 MF/COMM = Multi-family home in community setting
 LIV. FAC = Living Facility
 N. HOME = Nursing Home

**FIGURE 37**

Consumer Survey 1989

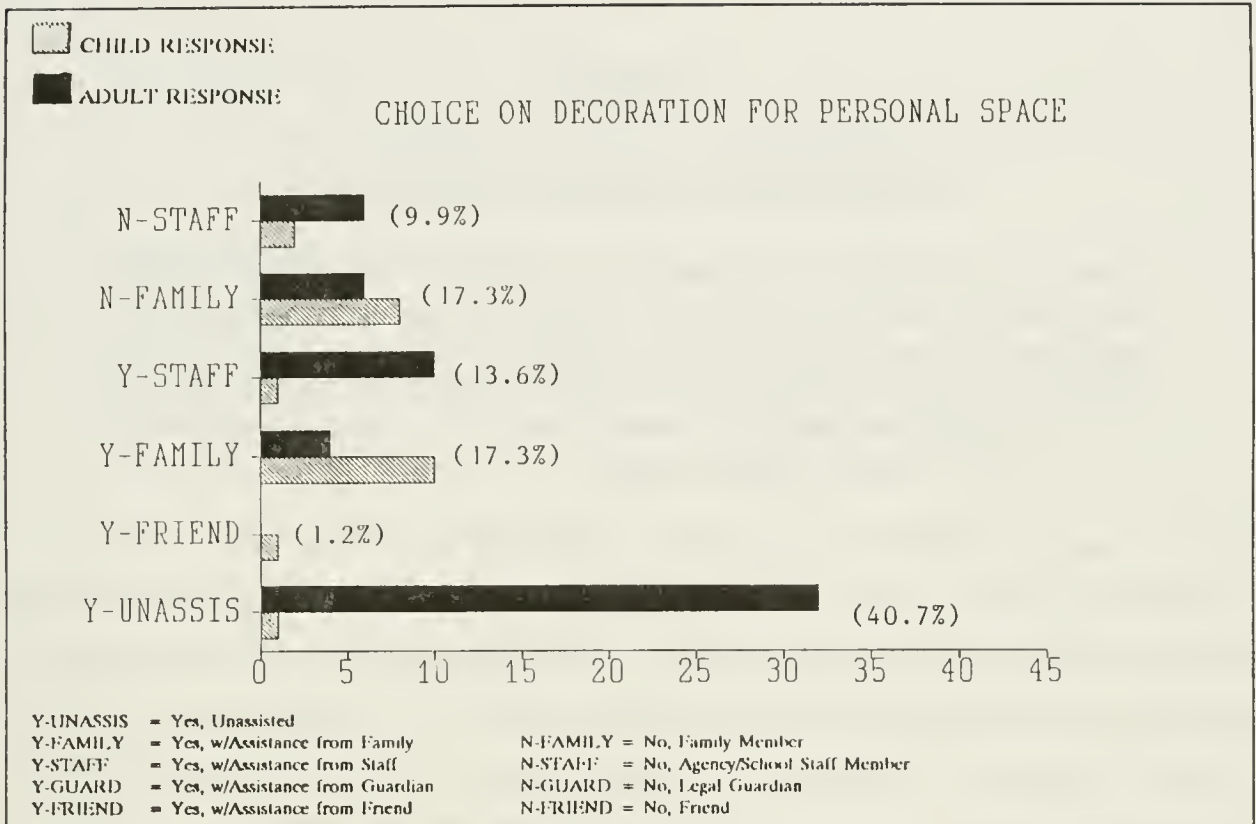


FIGURE 38

Consumer Survey 1989

HEALTH

A VISION OF HEALTH FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

Whether the disability community views itself as a vanguard in the movement for equitable health care financing for everyone, or as a tiny minority whose needs cannot be expected to be dealt with through the generic health care financing system may affect which groups are regarded as its allies, and may ultimately influence the direction of health insurance reform in the U.S.

(Access to Health Care, 1988)

Access to adequate and affordable health care is essential for all people to live independent and productive lives and to participate fully as members of their communities. Society benefits most when all people have a right to adequate health care so that they can reach their potential. An adequate health care system must provide comprehensive services that can respond to the range of health related needs of all people. Instead of meeting some minimum standards for the acute care needs of a nondisabled population, an adequate health care system must be prepared to respond to the health care needs of all people. While at least 35 million Americans have disabilities, many other people are "temporarily abled-bodied," and they or their family members will develop a functional disability or chronic illness at some time in their lives.

The generic health care system must provide appropriate acute care services, but it also must provide preventive care to minimize the development of certain conditions, diagnostic services for detection, and early intervention to prevent health problems before they begin to interfere with a person's normal activities and become more difficult to treat. Adequate health care must also provide rehabilitation services to enable a person to improve his or her level of functioning after a disabling condition and on-going maintenance services such as durable medical equipment, medical supplies, and personal assistance services. The health care services should be provided in an appropriate setting which increases the recovery time and minimizes interference with a person's normal activities.

The high cost of health care requires that all people have health insurance which protects against health care costs that can create a financial burden. Unlike other forms of insurance which offer protections and benefits that people do not necessarily have a right to, health insurance should be an entitlement because it is an essential link to health related services without which people cannot function.

In addition to health care services, an adequate health care system would provide people with the knowledge to act in ways that maintain their own health and to select appropriate health care professionals when their assistance is needed. Finally, the health care system should provide an adequate supply of competent health care providers who are knowledgeable about the health care needs of the person, experienced in treating their conditions, and adequately reimbursed for their services. Besides providing the services which people need to maximize their functioning, the health care system should distribute health care costs in an equitable way throughout the population, and minimize administrative costs without benefits.

Even though many people with developmental disabilities are in excellent health and have health care needs which are very similar to the nondisabled population, the presence of a disability may affect their health care needs in various ways. First, some health care needs may be directly related to the conditions causing the disability. Second, their health care needs may be more difficult to prevent or to treat because of the disability, and, third, they may have non-medical health related needs which are necessitated by the disability.

What distinguishes people with chronic conditions from other groups is the presence of predictable needs and higher levels of health care utilization for both acute care and different types of non-acute care services. The health care needs consist of (1) primary care, (2) medical rehabilitation, (3) developmental services, (4) on-going maintenance services, and (5) preventive services. Even if their primary care needs are similar to those of nondisabled persons, many people with chronic conditions have functional limitations which require rehabilitation therapies such as physical therapy, occupational therapy, and speech-hearing or language therapies in order to function normally. They may also require

on-going maintenance services such as durable medical equipment and assistive devices, personal assistance with self-care needs, drugs, disposable medical supplies, psychological services, and service coordination within the highly fragmented health delivery system in order to maximize their health and independence. In addition, although many people with chronic conditions are not sick, they may have "thinner margins of health" which must be carefully protected by preventive services which provide for early detection and treatment in order to avoid unnecessary complications and secondary disabilities.

Without appropriate health related services, some people with disabilities would not be able to live at home while others would not be able to get around, or would not be able to work, or to participate in the community. An appropriate wheelchair is as important for mobility as legs are for walking, an augmentative communication device is as important for talking as a voice, and rehabilitation therapies can make the difference between living independently or remaining dependent both physically and psychologically.

While our society has created various technologies and services which can increase survivability and compensate for different disabilities, access to those services depends on financing mechanisms like health insurance which have the potential of spreading costs in an affordable way. Operated under a profit motive, however, and financed largely by employers with publicly-subsidized premiums, private health insurance has evolved restrictive definitions of "medical necessity" to limit access to acute care needs. Our society has to decide whether these health related services should be funded through private insurance, or whether they will be financed through public programs or some combination.

Because developmental disabilities represent life-long conditions which cannot be "cured," it is important that health care services are provided in a community based way that does not interfere with normal life activities. For children with special health care needs, health related services should be family centered enabling the family to fulfill its obligations to its members. Family centered care maximizes family control, protects the integrity of the family unit and unites the technical knowledge of the professional with the intimate knowledge and personal commitment of the parents (Nelkin, 1987). For

working-age people, health related services may be needed which support the individual's independence from the family.

Unlike people with acute care problems that are expected to soon recover and resume their normal activities, people with life-long disabilities need health related services which do not interfere with their normal activities. In fact, they need services which empower them to manage their disabilities so that they can live as independently as possible in their own homes, function productively on their jobs, and participate as active members of their community.

The problem is that the health care system is built on an acute care model. To receive health care services a person is expected to assume a "sick role" in which he or she passively conforms to the requirements of the health care provider. We are often tolerant of the indignities which this creates because most acute care needs are temporary and the "patient" is expected to recover from the sick role. For people with life-long disabilities, however, health related services must be delivered in a way that minimizes interference with normal activities.

People with developmental disabilities need access to preventive care, rehabilitation and developmental services, durable medical equipment, as well as primary care to maintain their health. These services should be provided through an interdisciplinary team when necessary, and provided in the least restrictive setting to facilitate independence, productivity, and integration. It is unacceptable that people should be subjected to institutionalization because of the requirements of funding sources for health care. To ensure access to appropriate services it may be necessary to establish a clearly defined locus of responsibility which can assess health related needs in an interdisciplinary way, involve the person with disabilities and his or her family in service planning, coordinate the services provided by different providers, and facilitate the coordination of different funding sources. Flexible funding may be essential to enable people with disabilities and their families to choose appropriate providers and to maintain needed contact with them.

People with disabilities should have access to health care providers who are knowledgeable about their special health care needs and comfortable relating to people with disabilities.

BARRIERS TO THE VISION OF HEALTH FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

Social/Economic/Demographic Trends and Barriers

* The health care system is in crisis. Health care costs are continuing to rapidly rise, generating pressure for the major payors of health care to emphasize cost containment. This has led to greater cost-shifting to the health care user and more restrictive health insurance. It has also led to greater use of health maintenance organizations (HMOs) and capitated payments which create special problems for people with disabilities. While improvements in the health care system have increased the survivability of people with disabilities, there are growing obstacles to their access to health care.

- Health care cost are growing by \$50 billion a year, accounting for over 11.2 percent of the Gross National Product in 1987 (HCFA, 1988).
- Employers are concerned about rising health insurance premiums of close to 20 percent in 1988, which cuts into their profits and undermines their capacity to compete.
- The uninsured population has grown to 37 million people, especially among poor children, pregnant mothers, and working-age people with pre-existing conditions such as chronic health conditions or life-long disabilities.
- Health care providers are facing uncompensated care of approximately \$10 billion a year, which is disproportionately burdening public and non-profit providers that serve low income people (American Hospital Association, 1967).
- Consumers are concerned about higher premiums, deductibles, and co-payments, inadequate coverage, and the growing number of uninsured people.
- The federal government is concerned about the prospects of a growing number of people being dumped from private health insurance because of poverty or pre-existing health conditions.

* Caught in the vise of cost-containment, people with disabilities are increasingly vulnerable to restrictive medical underwriting practices of insurers for small groups and individual plans on the one hand, and the use of medical testing by large employers on the other hand. People with disabilities or chronic illness are increasingly squeezed between a private health insurance system which is designed to charge according to the probability of risk, and a public health care system which subsidizes health care on the basis of age, poverty status, and an inability to work.

- Risk avoidance by the private health insurance industry reduces the spreading of risk throughout the population and increases the demand for public health care.

- The move from community rating to experience rating has segmented the insurance market. People with higher risks are increasingly isolated from people with lower risks.

- Increased use of medical testing and advances in the technology of predictive tests are likely to be used by the private insurance industry for denying people health insurance coverage rather than for expanding access to preventive services.

- To promote cost-containment, the major payors of health insurance have resisted cost-shifting by health care providers which reduces their capacity to provide uncompensated care.

- Many people with disabilities and their families have been forced to bankrupt themselves in an effort to meet ongoing health care costs, often leading to unnecessary and expensive institutionalization.

* Many people with disabilities have higher health care costs than people without disabilities. The health care costs are higher because of the greater use of acute care services, rehabilitation services, and on-going maintenance services. The extent of the health care costs depends on the scope of the definition of health care. Health care costs may also be higher for a person with disabilities if: (1) the health condition which causes the impairment also causes other health problems; (2) the disability interferes with prevention or treatment of the underlying health condition; (3) health related services are required to deal with the disability.

- A Health Care Financing Administration (HCFA) study found that Medicare beneficiaries in the Adult Disabled Children category (the majority of whom have mental retardation) used hospitalization considerably less than SSDI beneficiaries in the Disabled Worker category. In fact, it appears that the rate of hospitalization is actually lower for persons between 35-64 years old among Adult Disabled Children than among the nondisabled population. It is likely, however, that this fact is misleading because a large number of Adult Disabled Children live in ICF/MRs which may provide the services that nondisabled persons may enter a hospital for. The mortality rate for Adult Disabled Children is actually higher than the rates for the general population, although considerably lower than the rate for SSDI beneficiaries among Disabled Workers (Lubitz & Pine, 1986).
- Data are generally lacking on the health care costs associated with specific chronic conditions. Nevertheless, NMCES data (1977) reveal that the average costs for inpatient hospitalization are more than six times greater for people unable to carry on their major activity than for people without limitation. In addition, the average costs for ambulatory physician contacts are almost three times greater, prescription drugs are five times greater, and the medical equipment and supply costs are six times greater for persons unable to carry on their major activity compared to persons without limitation (Access to Health Care, 1988).
- A recent survey of children with severe or profound levels of mental retardation in special education programs found that one-fourth of the children required at least one hospital stay in the course of a year for an average cost of \$6583. This random sample of 326 children in special education programs focused exclusively on children with IQs below 35. Although this sample is clearly not representative of most people with mental retardation, of whom 95 percent have IQs above 35 and 85 percent have IQs above 50, the study revealed that 26 percent of families with profound or severe levels of mental retardation had out-of-pocket expense for health related services which exceeded 5 percent of their family incomes and 15 percent of families had expenses which exceeded 10 percent of their family income. This contrast with 2.7 percent of the private insured population

under 65 who had out-of-pocket expenses which exceeded 5 percent of their family income in 1977 (Farley, 1985). Moreover, families of children with mental retardation and physical disabilities were three to four times more likely to experience out-of-pocket costs over 5 percent or 10 percent of their income than families of children with mental retardation without accompanying physical disabilities. Among all children with severe or profound levels of mental retardation who had private health insurance, the private health insurance paid approximately 50 percent of their medical expenses, uncompensated care accounted for 25 percent, families contributed around 15 percent, Medicaid paid about 5 percent, the state Program for Children with Special Health Care Needs contributed around 1 percent, and other payors provided around 5 percent (Birenbaum, Guyot & Cohen, 1985).

* As long as private insurers are permitted to view disability as a pre-existing condition with predictable higher health care costs, they have an incentive to reject people with disabilities, impose pre-existing condition exclusions, or raise premiums, sometimes to an unaffordable level.

- Insurers are not required to provide health insurance to people who need it at an affordable price.

- It is not precisely known how many people with disabilities have inadequate insurance although anecdotal evidence abounds.

* The health care costs are not well known for people of different ages and levels of severity, and different disabilities.

- The lack of data reflects the limitations of national surveys which have difficulty both identifying persons with low prevalence conditions and measuring health care costs from self-reported data.

* Private health insurance has evolved in the U.S. to cover acute medical needs, not ongoing maintenance needs.

- Blue Cross and Blue Shield were originally created by hospitals and physicians during the 1930s to secure reimbursement for the medical services which they were prepared to

provide as the Depression reduced people's ability to pay for needed services (Access to Health Care, 1989).

- The public policy objective of linking health insurance to employment appealed to employers, unions, insurers, and providers because it made access to health care a negotiable item between employers and unions, it simplified the administrative burden of collecting premiums for private insurers, and it protected health care providers from government control over health care costs. The downside is that it isolated people with the greatest health care needs, elderly persons and many people with disabilities who are not involved in employer groups, and it segmented the labor force into unequal size groups with limited capacities for distributing chronic health care needs.
- Access to private insurance depends largely on the size of the group with whom one shares risk, not on one's medical condition. Although the majority of employees work for large firms with over 500 employees, 75 percent of all employers have fewer than 10 employees (ICF, 1987). This means that three-quarters of employers have a very limited capacity to share risks.
- Private health insurance covers 36.9 percent of hospital care and 43.4 percent of physician services but only 11.3 percent of durable medical equipment, 13.8 percent of non-durable medical supplies, and 26.5 percent of other professional services that many people with disabilities depend on (Health Care Financing Review, 1988).
- There is also an institutional bias among both private and public third-party payors to limit coverage to people whose health condition is of sufficient severity to require hospitalization. This institutional bias limits access to covered services for many people with disabilities, and results in many services being provided in an institutional setting which interferes with normal activities associated with living independently or productively.
- * Many people with disabilities do not have private health insurance even when employed.
- Among working-age people with a "work disability," 84.6 percent have private insurance when working full-time, while 87.5 percent have private insurance when working part-time. For working-age people with mental retardation, the percentage with private insurance

drops to 51.7 percent for people working full-time and surprisingly appears to rise slightly to 59.1 percent for people working part-time (see below).

Working-age Persons with Mental Retardation, 1984

Employment Status	Health Insurance Status*			
	Private Insurance	Medicaid	Medicare	Uninsured
Not employed	31.0%	73.3%	28.2%	8.6%
Employed part-time	59.1%	27.1%	24.5%	30.1%
Employed full-time	51.7%	22.3%	36.3%	20.4%

*These percentages represent duplicate counts if a person has more than one form of health insurance.

Source: Calculated from unpublished 1984 SIPP (Survey of Income and Program Participation), Wave 3, data analyzed by Bureau of Economic Research at Rutgers University.

The lower percentage of private insurance for people with mental retardation may be attributable to a failure to distinguish between competitive employment and sheltered employment or it may reflect that many people with mental retardation are employed in marginal jobs with no fringe benefits. Equally important is the fact that among working-age people with mental retardation, 20.3 percent are uninsured when they are employed full-time, while 30.1 percent are uninsured when employed part-time compared to only 8.6 percent who are uninsured when they are not employed.

* The move toward capitated payments has been encouraged as a cost-containment strategy by both private and public payors of health insurance. One area where capitated

payments are used is in health maintenance organizations (HMOs). The impact of HMOs on people with disabilities or chronic illness needs to be closely monitored.

- HMOs offer limited benefits for extensive hospitalization or rehabilitation.
- Primary gatekeepers in HMOs are often not sufficiently knowledgeable about special health care needs nor empowered to authorize referrals to specialists who are not affiliated with the HMO (Access to Health Care, 1989).
- Administrative control mechanisms that are designed for acute care needs can disrupt the continuous treatment needed for certain chronic conditions.

Public Health Care Program Issues

- * Although public health care programs play an important role in substituting for private health insurance, there are many critical limitations in public health care programs. The public health care programs consist of Medicaid, Medicare, and federal block grant programs including Programs for Children with Special Health Care Needs (PCSHCN), Part B/H of Education for Handicapped Children's Act, and Vocational Rehabilitation.
 - Medicaid is the largest public health care program for people with developmental disabilities. Among persons with limitation in major activity, Medicaid covers 22.7 percent of children and 14.1 percent of persons 18-64 years old. The Medicaid program was established as Title XIX of the Social Security Act in 1965 and is jointly financed by the federal and state governments and administered by the states.
 - The basic state Medicaid plan consists of federally mandated and optional services which the state is obligated to provide to all people who meet the basic financial and disability criteria for eligibility. Because the Medicaid program is state administered, states can set the "amount, duration, and scope" for all Medicaid services.
- * Medicaid has the potential of being the most comprehensive health care program which can cover most of the health related needs of people with disabilities.
 - Federal and state laws restrict Medicaid to people who meet the income, asset, and disability criteria for eligibility.

- * Health care providers face many disincentives to serve people with disabilities.
 - Medicaid reimbursement levels are generally far below the reasonable and customary rates even though providers may have to spend considerably more time with people with disabilities, and are required to accept the Medicaid reimbursement as payment in full. The greater time may be necessary because of functional limitations, communication barriers, elaborate follow-up requirements, need for interdisciplinary models of care, etc.
 - The largest federal health care program is Medicare which was established as Title XVIII of the Social Security Act in 1965. It is financed largely by a payroll tax on all employed individuals and is available to people once they turn 65 years old. Since 1972, people with disabilities are eligible for Medicare if they are SSDI recipients or are dependents of Social Security recipients who have retired, died, or themselves become disabled workers. Approximately 10 percent of Medicare recipients are people with disabilities between 18-64 years old. The only children under 18 who are eligible for Medicare are those who require kidney dialysis. The End Stage Renal Dialysis program is the only disease-specific program in Medicare and it covers people of all ages. Many adults with developmental disabilities become eligible for Medicare as Adult Disabled Children.
- * People who qualify for Medicare on the basis of disability are eligible only after a 24-month waiting period.
 - This federal requirement of a waiting period was established for cost-containment purposes and to avoid creating a disincentive for private insurance to cover health care for a recently disabled worker.
 - Unfortunately, as many as one-third of SSDI beneficiaries are uninsured at some point during the two-year waiting period for Medicare (Access to Health Care, 1988).
 - Many SSDI beneficiaries die before becoming eligible for Medicare (Lubitz & Pine, 1986).
 - The waiting period for Medicare can interfere with early medical rehabilitation which is essential for helping people increase their functional capacity.

* Medicare benefits do not include many of the health related services which are crucial to the ongoing health support for people with disabilities. Although the Medicare Catastrophic Act of 1988 will finally add prescription drugs as a Medicare benefit in 1991 with a \$600 deductible, and finally provides a cap on out-of-pocket expenses for acute care services, many services for on-going health needs remain unaddressed by the Medicare Catastrophic Act of 1988.

- While Medicare will cover wheelchairs as durable medical equipment, Medicare does not cover augmentative communication devices for a person who does not have the capacity to speak or hearing aids for a person who has difficulty hearing.

- Medicare will not cover rehabilitation therapies for people who are not expected to make measurable functional progress even though they are likely to functionally degenerate without the rehabilitation therapies.

- SSDI beneficiaries who earn over the Substantial Gainful Activity level of \$300 per month could lose access to Medicare after they have exhausted their nine-month trial work period, 15-month extended period of eligibility, and 24-month Medicare continuation after termination of their SSDI benefits.

- In the absence of a 1619 type protection in the SSDI program, the loss of Medicare for people with permanent disabilities could create a disincentive for SSDI beneficiaries to enter the labor force if they anticipate difficulties purchasing private health insurance. While the immediate loss of SSDI benefits after the trial work period is likely to be a more powerful disincentive to work (see chapter on Income), a Medicare buy-in program could increase access to health care for SSDI beneficiaries who choose to enter the labor force.

- Program for Children with Special Health Care Needs (PCSHCN). This is part of the oldest existing federal health care program established as Title V in the Social Security Act of 1935 which became part of the Maternal and Child Health Block Grant in 1981. PCSHCN has a long history of providing health related services to children with special

types of disabilities. As a state administered program, states have wide discretion in using these federal funds to serve children birth through 21 years old with special health care needs. The programs originally served children with orthopedic impairments but Congress sought to broaden the target group by changing the name from Crippled Children's Services (CCS) in 1986.

Most states use their PCSHCN programs for some combination of: (1) gap-filling certain health related services (e.g., clinical therapies and specialty medical services) that are available in private health insurance but not accessible to certain populations, (2) case management and team conferencing or coordination of care provided by different health care practitioners that is extremely important in an increasingly fragmented health care system but is often not reimbursable under private health insurance, and (3) system-building through advocacy for expansion of community-based services, training of health care providers through continuing education curricula, planning the coordination among public health care programs, and development of written quality standards for serving children with special health care needs for the health care providers with whom PCSHCN has contracts (Ireys & Eichler, 1988).

* Fiscal constraints limit the capacity of PCSHCN programs to provide a gap-filling role for all children with special health care needs. To limit the great demand for scarce public funds to supplement the inadequacy of acute care private health insurance, many states have arbitrarily limited eligibility to this program by targeting different diagnostic groups of ages of children. Many states ration their limited PCSHCN service dollars by favoring younger children over older children or by excluding from coverage such major childhood disabilities as diabetes, cancer, asthma, sickle cell anemia, mental illness, or developmental disabilities. This has created inequities in serving certain groups while rejecting others who are just as deserving. As a result, political advocacy has influenced the resource allocation more than a rational planning process which is guided by general principles oriented to improving access to health care for all children with special health care needs.

- States have total discretion in determining how much of their Maternal and Child Health block grant funds are allocated to PCSHCN activities.
- The strongest public mandate for health care to people with disabilities is perhaps contained in the Education for Handicapped Children's Act of 1975 (P.L. 94-142) which guaranteed all school-age children 5-17 years old with handicaps the right to a free public education. Amendments to EHA have extended the special education mandate to all handicapped children ages 3 through 21 years in the least restrictive environment. As long as a service is needed by a child to obtain special education, and the educationally-related service is identified in the child's Individual Education Plan (IEP), the public school system is required to provide the educationally-related service at no cost to the family (Federal Register, 1980). As interpreted by the 1984 Supreme Court decision in the Tatro case, a child with spina bifida was entitled to catheterization in the classroom as an educationally-related service because it enabled the child to receive a public education. Although this special education mandate refers only to services which enable the child to participate in public education, the mandate is independent of the family's income.

Among the services which children with disabilities may have a right to receive as educationally-related services are: physical therapy, occupational therapy, speech therapy, and psychological and nursing help and assistance in the classroom. The public school's obligation to provide educationally-related services extends to all children with disabilities who need special education whether they are served in a public or private school.

* Part H of the Education of Handicapped Act. Recognizing that the EHA mandate did not cover infants and toddlers from birth through three years who may need special services for developmental delays, Congress passed P.L. 99-457 (Part H) as an amendment to EHA in 1986 which extends the mandate to educationally-related services to infants and toddlers who are developmentally delayed. States have received federal planning money to set up a system to implement Part H by October 1991. This represents an important

effort to expand the mandate implicit in EHA to younger children regardless of family income.

- Among the developmental needs which the early intervention program is supposed to address are: physical development; cognitive development; language and speech development; psycho-social development; and self-help skills. Health services are included only to the extent that they are "necessary for the infant or toddler to benefit from the other early intervention services." The intent of this legislation is for the federal funds to be used to establish a service system, and not to pay directly for individual services, except as a "payor of last resort."
- The Part H program may create some important precedents by: (1) extending federal responsibility for the developmental needs of infants and toddlers regardless of family income; (2) developing a methodology for assessing the range of developmental needs associated with various chronic conditions; (3) providing a state-level mechanism for coordinating services provided by different providers and funded by different sources; and (4) creating a public capacity to supplement the health related services provided by private insurance and public programs.

* Vocational Rehabilitation (VR) is an important source of funding for health related services that would enable a person with a disability to seek employment. Once a person is rehabilitated and placed on a job, however, the case is closed and there is no further follow-along service.

- Approximately 20 percent of VR service dollars were used for restorative health related services in 1986 (RSA, 1988).
- While VR funding can pay for various health related services like adaptive equipment, prosthetic devices, etc., a person with a permanent disability may have trouble getting coverage for these services through private insurance.
- Some state VR agencies will allow a person to apply again to VR to pay for certain gap-filling services if they would not be able to continue employment without them.

* Public policy affecting Private Health Insurance. Since almost two-thirds of all people with disabilities are, in fact, covered by some form of private health insurance, it is important for DD Councils to consider not just how the state and federal governments can improve specific public health care programs, but how public policy can be used to more effectively require private health insurance to respond to the needs of people with disabilities. This includes issues of employer and insurer regulation, tax policy, and standards for appropriate health care, etc. To concentrate exclusively on developing public health care for persons rejected by private health insurance reinforces the tendency of private insurers to dump high risk people into public programs rather than to spread risk throughout the population.

- Insurance is supposedly regulated at the state level but only two states (Hawaii and Massachusetts) have passed laws requiring employers to provide health insurance.

- Self-insured employers are exempt from state regulation due to the federal Employee Retirement and Income Security Act (ERISA) law which ironically does not contain any federal standards for health insurance.

- Private insurers are permitted to develop and utilize their own actuarial methods to assess risk, and to exercise wide discretion in rejecting applicants, imposing pre-existing condition exclusions, or raising premiums.

* Private health insurance is regulated at the state level. States can require private insurance to meet certain conditions.

- There are over 645 state mandates which require private insurers to provide certain benefits. State laws and regulations determine which types of providers are eligible to receive private insurance, what services must be covered, who must be considered beneficiaries of the health insurance policy, and under what conditions the health insurance plan can be continued. State mandates which directly benefit people with developmental disabilities include a newborn mandate which requires health insurers to cover newborn children from the moment of birth rather than to wait one month to determine whether the infant is "insurable"; a mentally or physically handicapped mandate which allows adults

with mental or physical disabilities to remain as dependents on their parents' health insurance policy if they continue to live in their parents' households and are financially dependent on their parents; provider mandates such as access to physical, occupational, or speech/hearing therapists, and various benefit mandates such as access to home health care, orthotic/prosthetic devices, etc. (see Access to Health Care, 1989). At least one state (Massachusetts) is considering a bill to create a mandate for early intervention services.

- * States can create insurance pools that spread risk throughout the population.
- Some states are planning state insurance plans that will provide coverage to uninsured persons and people in small employer groups or who are self-employed.
- It is possible to conceive of a state insurance plan that combines people with disabilities with uninsured people, persons in small employer groups, persons in Medicaid, and state employees.
- * Fifteen states have created high risk pools for people who are rejected by private insurers because of a pre-existing condition.
- While high risk pools allow some people to purchase health insurance who would otherwise not be able to, the high risk pool creates certain problems (see Access to Health Care, 1989).
- By concentrating people with high risk in one pool which does not contain people of lower risk, the average cost is high which creates pressure for high premiums, high deductibles, and high co-payments. High risk pools are generally very expensive for the consumer. Typically, consumers have to pay at least 150 percent of an average premium, plus a high deductible, and co-payments of 20 percent. This can result in out-of-pocket costs which often exceed \$3,000-\$4,000 per year. As a result, high risk pools are unaffordable to many people without a public subsidy.
- By modeling high risk pool benefits after major medical insurance plans for people without disabilities, many health related services needed by people with disabilities are not covered by high risk pools.

- The deficit generated by the high risk pool above the premiums collected is distributed among private insurers who in turn are provided a tax credit in many states corresponding to the size of their assessment. This financing mechanism in effect subsidizes people who can afford the high premium, deductible and co-payment while penalizing those who cannot. Moreover, the federal ERISA law prevents states from requiring contributions to the high risk pool from self-insured employers which excludes the fastest growing sector of group insurance policies.
- The establishment of high risk pools runs the danger of legitimating the exclusion of so-called high risk people from private health insurance and may create incentives for dumping by private insurers.

Right/Access Issues

- * Although the American public increasingly views health care as a right and the health care system as operated to ensure access to comprehensive health related services, the right to health care remains underdeveloped in public policy.
- Health care was omitted from the Social Security Act in 1935 because President Roosevelt did not want to jeopardize tenuous support for other sections of the Social Security act in the face of opposition from the American Medical Association and the American Hospital Association to federal regulation of health care (Access to Health Care, 1989).
- As recently as 1945, only one-quarter of the U.S. population had any health insurance, and it wasn't until the mid-1960s that the majority of Americans had more than hospitalization insurance (Health Insurance Association of America, 1988).
- Employers are not required to provide health insurance to their employees or to their dependents as they are required to provide social security contributions, workers compensation, unemployment compensation, and minimum wages.
- The right to health care is available only to people over 65 who are eligible for Medicare. This is limited to acute care needs, however.

- The linkage of Medicaid to SSI in most states provides access to health care for many people with disabilities who are eligible for SSI. In 14 states referred to as 209(b) states, however, a more restrictive eligibility criteria is used to determine eligibility for Medicaid.
- Many people with disabilities who do not meet the income, asset, and disability criteria for SSI are not eligible for Medicaid even when private health insurance is unavailable to them or inadequate for their health care needs.
- The strongest public mandate for health care to people with disabilities is perhaps contained in the Education for Handicapped Children's Act of 1975 (P.L. 94-142) which guarantees all children with handicaps a free, publicly supported education. As long as a service is needed by a child to obtain special education and the related service is identified in the child's Individual Education Plan (IEP), the public school system is required to provide the educationally-related service at no cost to the family (Federal Register, 1980).
- Planning efforts to implement Part H of EHA represent an important effort to expand the mandate implicit in EHA to younger children regardless of family income.
- There is growing support among health care providers, labor unions, employers, and public opinion to explore the advantages of a National Health Insurance system as developed in Canada. When it is recognized that private health insurance actually accounts for less than one-third of the total personal health care expenditures in the U.S., while government contributes 39.6 percent and direct patient payments account for 27.8 percent in 1987 (HCFA, 1988), there may be greater interest in examining the advantages of national health insurance.
- A Louis Harris survey of public opinion in the U.S., Canada, and Britain in 1988 revealed that 61 percent of Americans said they would favor a system like that in Canada described in the survey as one where "the government pays most of the cost of health care for everyone out of taxes, and the government sets all fees charged by hospitals and doctors." Interestingly, this preference was shared by the mainstream of American society: the middle income population and business and government executives. Among those Americans who were unable to get needed services because of financial barriers, only 36

percent were uninsured, suggesting that the other two-thirds had inadequate insurance coverage (Blendon, 1989).

Fiscal/Resource Issues

- * Fiscal issues underlie most of the limitations of public health care programs.
- The two-year waiting period for Medicare was largely created to contain costs and the opposition to its elimination is that it could increase Medicare costs by 44.7 percent for SSDI recipients over a ten-year period (Bye & Riley, in press).
- States are generally resistant to amend their Medicaid plans to add optional services or increase benefit levels because Medicaid requires them to extend those services to all people who meet the eligibility criteria.
- Although the federal government provides a higher Medicaid matching rate for poorer states, the wealthier states continue to spend more Medicaid dollars per capita than the poorer states. The differential matching rate does not increase the capacity of the poorer states to generate their own revenues which would be required to expand the Medicaid program.

Data/Monitoring/Accountability Issues

- * The determination of who is eligible for health insurance has largely been left to the discretion of private insurers who are more concerned about making a profit than about spreading health related costs equitably throughout the population.
- Even though the federal government is expected to provide a subsidy of over \$37 billion in 1989 to employers who contribute to the health insurance of their employees, by permitting the use of tax-free dollars, the federal government has not specified the minimum essential features of a group health insurance plan. The Kennedy bill would ensure that employers provided health insurance which contained minimum benefit levels, catastrophic protection, etc.

* The federal and state governments do not regulate the medical underwriting process or maintain actuarial statistics which the insurance industry must use. Often the insurance industry claims it cannot develop a premium for a specific disability group because it does not have sufficient actuarial data on that group which it has continued to deny for insurance. People who are blind challenged the actuarial statistics of private insurers and succeeded in winning mandates that they should not be discriminated against unless supported by actuarial data. Unfortunately, there are no standards to determine whether the private insurers are discriminating in their use of actuarial data.

At this stage in the movement for health insurance reform, it is important that adequacy of private and public health insurance be carefully monitored. Existing national surveys do not reveal the extent to which people with specific disabilities have pre-existing condition exclusions or pay a catastrophic percentage of their income in out-of-pocket costs. These studies should be conducted at the national, state, and disability group level.

In addition to data collection on the adequacy of private insurance, states have an important role to monitor the quality of health care available to people with disabilities. This means the level of training, accessibility, and availability of providers.

* The disability movement has a unique opportunity to influence the way other groups perceive health insurance reform.

- Because people with disabilities or chronic illness are likely to have higher health care costs, they are very sensitive to the principles of affordability and the equity of health care financing.

- Because people with disabilities or chronic illness are likely to need a range of health related services that extends beyond acute care, they are in a critical position to help broaden the definition of health care to include preventive services, rehabilitation services, and long-term supports.

- Because people with disabilities recognize how barriers to health care create obstacles to employment and to meaningful participation in the community, the disability movement can sharpen the issue of health care as a right which all citizens should be entitled to.

NADDC RECOMMENDATIONS

1. Health care financing policies must be changed in order to promote universality, comprehensiveness, equitable financing, and cost-controls.
2. Congress should create financing mechanisms that ensure that all people have equal access to the health care services which they need.
3. An equitable health care financing system would protect people from excessive health care costs in relation to their incomes. Families of people with disabilities should not have to pay a greater percentage of their income for health care than families without disabilities. Health insurance should protect people from all health care costs, not just unpredictable health care costs. The distribution of disabilities is itself an unpredictable condition for which all citizens need comprehensive health insurance protection. The eligibility of people for health care services should be based on health care needs, not income level, age, or the inability to work. Premiums should be based on income level (taking into account family size and disability related expenses), not on the probability of risk. Out-of-pocket costs for deductibles or co-insurance should be limited to a fixed amount or a certain percentage of a person's income. The financing mechanism should protect against excessive annual and lifetime out-of-pocket costs which can impoverish a family.
4. The federal government could prohibit insurers from excluding, terminating, or otherwise limiting any individual from coverage based on a pre-existing condition. It could also prohibit experience rating which involves the setting of premiums on the basis of previous individual or group claims. To achieve those objectives, Congressman Doug Walgren (D-PA) has introduced the Federal Health Insurance Equity Act of 1989 (H.R. 2649).
5. It is important for data to be collected on the limitations of private and public health insurance for people with disabilities. Surveys should be conducted at that national, state, and community levels to more precisely measure; the extent of the limitations of private health insurance on people with disabilities and the impact on

both their lives and on the social costs to society. The health insurance roulette wheel in Figure 1 provides a summary of several of the danger zones associated with private health insurance for people with pre-existing health conditions. Like the proverbial turn of the roulette wheel, whether one develops a pre-existing condition is likely to be determined by chance and the specific danger zone one lands on is likely to be influenced by the intervention of money.

6. It is important to measure annual costs for all health-related services and to project to lifetime costs; secondly, it is important to distinguish between total costs and out-of-pocket costs in relation to family income in order to measure the financial burden of developmental disabilities on the family; and, fourthly, it is important to measure other financial costs associated with providing support for people with developmental disabilities such as income potential that was sacrificed because a family member could not seek employment or could not change jobs for fear of losing health insurance.
7. To avoid interfering with the integration, independence and productivity of people with chronic conditions, it is necessary to broaden the definition of health care beyond acute care services and reverse the institutional bias so that people with disabilities can receive health related services in their own homes and community settings. It is also necessary to create a financing mechanism for equitably distributing the health care costs throughout the entire population.
8. People should not have to sacrifice their access to health insurance by working.
9. Because public policy has encouraged employment-linked health insurance, an employer mandate, such as Senator Kennedy's (D-MA) Basic Health Benefits for All Americans Act of 1989 (S. 768) which requires all employers to provide health insurance to their employees and dependents would significantly reduce the size of the uninsured population at minimal cost to federal and state governments. It is estimated that 24 million uninsured persons would be covered if all employers were required to provide health insurance to their employees and their dependents.

10. For people who are eligible for SSI, there should be a greater effort to use Section 1619 of the Social Security Act to qualify for Medicaid when they are employed. In 1986, the federal government removed a crucial disincentive to work for SSI recipients by permanently adding Section 1619 to the Social Security Act. This allows SSI recipients to earn a level of income up to the value of the cash assistance, Medicaid payments, and the publicly-funded attendant care benefits that they would have been eligible for through SSI and Medicaid by not working. Reflecting differences in cash assistance levels based on additional state supplements to SSI and differences in the services available in Medicaid programs in different states, a disabled person on SSI can earn up to \$19,965 in California, \$19,396 in New York, \$16,177 in Wisconsin, and \$19,092 in Massachusetts while still being eligible for Medicaid in 1989 (SSA, 1989). Prior to Section 1616, SSI recipients would lose eligibility for SSI and Medicaid as soon as they earned over the Substantial Gainful Activity level of \$300 per month.
11. It is important for states to monitor the impact of HMOs on people with chronic health conditions in order to consider whether it may be necessary for provider risk to be separate from prepayment for high risk populations or for HMOs to make certain modifications in their administration controls for chronic care.
12. Given the barriers to access which HMOs impose on enrollees, people with disabilities should not be required to participate in an HMO.
13. Make sure states consider all of their options for using Medicaid. These include: (1) amendment to the basic state plan; (2) utilization of the higher benefit levels in the Early Periodic Screening Diagnosis and Treatment program (EPSDT) for low income children from birth through 21 years; and (3) Medicaid waivers for home- and community-based services. A basic Medicaid plan amendment creates an entitlement for all people who meet the eligibility criteria to the services provided in the state plan while a Medicaid waiver allows greater flexibility in the types of services which can be offered but the eligibility is limited to persons who are at risk

of institutionalization and is subject to a time limited approval process by HCFA limiting costs and numbers of persons.

14. States can broaden eligibility for Medicaid by: (1) disregarding family income if a child is at risk of institutionalization (TEFRA 134 option established in 1982); (2) raising the income threshold up to 185 percent of poverty for pregnant women and children; (3) removing resource tests; (4) expanding medically needy program; and (5) establishing a Medicaid buy-in with sliding scale premium.
15. States can make sure that Medicaid reimbursement levels are sufficient to remove disincentives for serving people with disabilities.
16. The federal government could permit states to use federal Medicaid dollars to make Medicaid benefits available to people on a sliding fee scale who do not meet the financial eligibility requirements for Medicaid. Senator Chafee (R-RI) has proposed the Med-America Act of 1987 (S. 1139) which would allow states to provide Medicaid coverage to people with pre-existing conditions regardless of their income who are rejected by private insurers. Med-America would allow states to: (1) cover all people under 100 percent of poverty at no charge to them; (2) cover people between 100-200 percent of poverty on a sliding scale premium up to 3 percent of their adjusted gross income; and (3) cover people above 200 percent of poverty who cannot purchase private insurance because of pre-existing conditions at a full community-rated premium reflecting the collective experience of all persons in the Medicaid buy-in program. The Medicaid buy-in program would also be available to small employers who cannot purchase affordable health insurance in the private market for their employees and dependents. Under the proposed Med-America bill, states would have the option of covering services provided through the home- and community-based waiver program through its Medicaid buy-in program.

Many of these concepts have been incorporated in Senator Kennedy's Basic Health Benefits Bill for All Americans Act of 1989 (S. 768) which proposes to phase-in Medicaid coverage for uninsured persons over 100 percent of poverty over

the next ten years. At least three states (Massachusetts, Wisconsin, and Maine) have developed or are planning state-funded Medicaid buy-in plans (without federal Medicaid dollars) to provide health care on a sliding fee scale to working-age people with disabilities and in one state to children with disabilities.

17. Medicaid reimbursement should reflect the time that providers must spend to provide quality care to people with disabilities.
18. People with disabilities should have access to health care providers who are knowledgeable about their special health care needs, experienced in providing care, and comfortable relating to people with disabilities. To ensure the availability of competent providers, it is important that health care providers are adequately trained and adequately reimbursed to compensate for disincentives to serve people with disabilities.
19. The federal government should eliminate the two-year waiting period for Medicare, or at least establish Medicare as a secondary payor for new SSDI beneficiaries.
20. In the interim, the federal government could extend the employer mandate for COBRA continuation coverage for 29 months for persons ending work as a result of disability which would permit SSDI beneficiaries to purchase continuation coverage if they are fortunate enough to have an existing group plan and if they can afford both the employer's premium and the employee premium while completing the two-year waiting period for Medicare. This has been proposed by Congresswoman Nancy Pelosi (D-CA) in H.R. 2308, 2309, and 2310 and would entail no cost to either the federal government or to employers. Under current COBRA continuation coverage mandate created in 1985, employers with 20 or more employees who do provide health benefits are required to provide the option of continued coverage under the employer's health benefits plan for up to 18 months after termination of employment if the employee can pay both the employer and employee share of the premium (Fuchs, 1989).

21. Remove the arbitrary exclusions in Medicare coverage on assistive devices and environmental controls which enable a person to improve his or her functioning or replace the function of a body organ.
22. Remove the arbitrary distinction between acute care and chronic care in determining eligibility for Medicare coverage.
23. Develop a long-term home care benefit under Medicare, as proposed by the late Congressman Claude Pepper (D-FL), which would be available to current Medicare beneficiaries and children with disabilities on the basis of functional limitations. In addition, make working-age people with disabilities eligible for long-term home care on the same basis as elderly people and children.
24. The federal government can create a Medicare buy-in which would permit SSDI beneficiaries who are "disabled and working" to buy-in to Medicare benefits. Congressman Steve Bartlett (R-TX) has proposed H.R. 8 that would allow Medicaid funds to be used to pay the Medicare premiums for persons earning below 150 percent of poverty and to subsidize the Medicare premiums on a sliding fee scale for persons with earnings below 300 percent of poverty (approximately \$19,000). Senator David Durenberger (R-MN) has proposed S. 320 that would require former SSDI beneficiaries to pay the entire Medicare premium subject to an 8 percent cap on their income. There should be a way to combine the Medicaid subsidy feature of the Bartlett bill for low-income earners and the 8 percent cap of the Durenberger bill in addition to reducing the amount of the Medicare Part A premium based on the previous financial contribution which SSDI beneficiaries have made to the Medicare Trust Fund through previous social security taxes.
25. The federal government should require states to allocate at least one-third of their Maternal and Child Health block grant to PCSHCN and to develop uniform eligibility criteria for PCSHCN services to all children with special health care needs. Although expending the eligibility will not eliminate the problem of rationing scarce

- resources, it will increase the accuracy of estimates of unmet need and increase the recognition of an advocacy role to expand federal and state dollars for PCSHCN.
26. Much of the effectiveness of PCSHCN programs will depend on improving the coordination among existing public programs like Medicaid's EPSDT, optional services, and waiver programs, the Part B program of the public school system, and the Part H program for early intervention for children from birth to three years old.
 27. States should make sure that the public school system is identifying all health related needs in the Individualized Education Plan (IEP) which impact on publicly supported special education.
 28. States should make sure that Medicaid pays for covered services provided to children who are dually eligible for aid under both Medicaid and the Education for All Handicapped Children Act as clarified by the Medicare Catastrophic Act of 1988.
 29. Based on the planning efforts in the states for Part H of EHA, it may be necessary for the federal government to allocate some federal funds for services identified in the Individualized Family Service Plan (IFSP) in order to encourage states to make a legally binding commitment to ensure that eligible children and their families receive the early intervention services needed.
 30. The capacity of states to access private health insurance funds for early intervention services may determine the willingness of states to create an entitlement to Part H services.
 31. The federal government may be able to increase the effectiveness of VR job placement by reimbursing VR for necessary follow-along services once a person has been rehabilitated and placed in employment under certain conditions. The VR program can better address the health related needs of working-age people who want to enter the labor force by improving its coordination with other service programs at the state level which can provide continuing support services for people after they have been placed in employment. The federal government should

consider various ways to use the disability benefits which an SSDI beneficiary would have been entitled to as a potential funding source for some of the health related services which an SSDI beneficiary needs to maintain employment

32. The public sector must regulate private insurance in order to ensure that comprehensive health care services are available and that health care costs are equitably distributed throughout the population.
33. States can try to use state health insurance mandates to broaden the scope of health related services covered by private insurance and to close loopholes in private insurance coverage that people with disabilities fall through.

While state mandates illustrate how the regulatory process can reduce gaps in private health insurance, this state-level process is at best uneven and reflects the political power of different interest groups at the state level rather than some overarching principles of comprehensiveness of benefits or equity in access or affordability. The greatest threat to state mandates, however, is not the arbitrariness of the political process or the general opposition by employers and insurers but the ERISA preemption. No matter how progressive state mandates might be, self-insured employers are not required to follow them. With the majority of group plans accounted for by self-insured employers, this is perhaps the major weakness of state mandates and underlies the necessity for federal regulation of health insurance.

34. Amend the federal ERISA law to allow state regulation of self-insured employers in regard to health insurance.
35. Develop federal standards for all health insurance plans.
36. States should consider the range of options which they have to prevent people from being rejected by private insurance or to distribute their costs in an equitable way before resorting to a high-risk pool.
37. States should develop financing mechanisms to spread risk throughout the population. If health care premiums, deductibles, and co-payments were viewed as

"taxes," it would be easier to see the inequity of requiring people with disabilities to pay higher taxes because they use more health care services.

38. States should consider state insurance pools which combine uninsured persons, people with pre-existing conditions, and persons in small employer groups who cannot purchase affordable or adequate health insurance in the private insurance market.
39. Other state pools which can distribute risk throughout the population are uncompensated care pools, catastrophic insurance pools, and public reinsurance mechanisms. Uncompensated care pools collect and redistribute funds to hospitals that have a disproportionate share of bad debt and charity care because they serve more people without health insurance. Catastrophic insurance pools protect people against medical expenses which exceed a certain level of their income. People with disabilities are vulnerable both to the definition of what constitutes an extraordinary financial burden and to the definition of what expenses to include in measuring out-of-pocket costs. Reinsurance mechanisms can reduce the economic disincentive which private insurers have to cover people with higher risk by compensating insurers for losses which exceed some threshold level.
40. A Medicaid buy-in program could be an appropriate financing mechanism if the Medicaid benefit plan was comprehensive, and if the premium structure could be designed on an affordable sliding fee scale, and if the reimbursement levels are adequate.
41. As long as improvements in health care programs are limited to surplus funds in these times of budget deficits, it will be difficult to consider anything but small incremental changes while the health care system stampedes out of control. It is necessary to consider strategies for redistributing the total health care expenditures which represented \$500 billion in 1987 or 11.2 percent of the Gross National Product in order to achieve the vision for our health care system.

42. The federal government should use its leverage to require group insurance policies to meet certain minimal standards in order to qualify for a tax subsidy.
43. The disability community has an important role in shaping the priorities for health insurance reform. Perhaps no other group has such a stake in defining community as the group with whom one shares risk.

MONTANA RECOMMENDATIONS

The primary source for Montana's recommendations is the Temple University Consumer Survey conducted by our state in 1989. Recommendations derived from the survey are followed by parenthetical reference to specific item numbers in the survey, indicating the percent of respondents dissatisfied with a particular service and the total number of respondents to that particular item. If the issue also arose during the public forums, that source is noted in the parenthetical reference as well.

1. The availability of quality, integrated, general medical services and emergency health services, particularly in rural areas, must be enhanced. Medical professionals should receive training in methods for effectively working with persons with disabilities and sensitivity regarding the dignity of persons with disabilities (Item 5.2: 20% of 30; Item 5.3: 19.2% of 68; forums).
2. An adequate health insurance and Medicaid reimbursement system must be developed which is affordable, minimally complex, and individualized to address unique clients' needs (Item 5.5: 27.5% of 29; forums).
3. Payments for medications should be increased, and improvements should be made in the quality of medication provision procedures (Item 5.8: 21.2% of 47).
4. Improvements in the quality of available genetic counseling and screening should be undertaken. Because of the distances which individuals must travel in Montana to receive such services, increased assistance in the area of transportation should be addressed (Item 5.9: 30% of 10).

5. Medicaid funding for mental health or counseling services specific to clients' needs must be increased in order to provide for adequate services for persons with disabilities (Item 6.4: 40% of 15; forums).
6. The costs for appropriate adaptive equipment are exorbitant. A system such as a local, regional, or national "clearinghouse" should be developed for acquiring low-cost equipment or securing the equipment at a reasonable cost through exchanges or resale of equipment no longer needed (forums).

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APPENDIX G

FIGURES AND TABLES

Level of Satisfaction with Services - Health

<u>Service</u>	Percentage of Participants Receiving <u>Services</u>	% Satisfied of those Receiving <u>Services</u>	% Dissat. of those Receiving <u>Services</u>
<u>Health Services</u>			
General Medical	78%	82%	7%
Dental	85%	87%	8%
Medicaid	65%	89%	3%

Level of Satisfaction with Services - Transportation

<u>Service</u>	Percentage of Participants Receiving <u>Services</u>	% Satisfied of those Receiving <u>Services</u>	% Dissat. of those Receiving <u>Services</u>
<u>Transportation</u>			
To work or school	81%	80%	11%
To nondaily activities	65%	80%	16%
For Leisure	58%	77%	21%

HEALTH IN \$URANCE ROULETTE



Drawing by Laura Wallace

"Step right up to the finest protection that voluntary private health insurance can offer!"

FIGURE 39

CIVIL RIGHTS

A VISION OF CIVIL RIGHTS FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

We hold these truths to be sacred and undeniable: that all men are created equal and independent, that from that equal creation they derive rights inherent and inalienable, among which are the preservation of life, and liberty, and the pursuit of happiness.

Thomas Jefferson
Original draft of the
Declaration of
Independence 1776

The exercise of full civil rights begins with the understanding of the individuality of every human being and the acceptance by society of the principle of one level of humanity and citizenship.

The protections of the United States Constitution have, as their purpose, to prevent individuals from untoward intervention by government, to provide individual freedom of choice, and from discrimination, and recourse to redress grievances.

American citizenship encompasses a panoply of privileges, entitlements, and responsibilities: voting, decision-making, choice of how, where and with whom one lives, control over personal property and finances, choice of friends, privacy, marital and sexual rights, the right to bear and raise children and to serve on juries, contractual and consumer rights, employment opportunities, educational rights, medical treatment choices, and the means to secure and protect these rights. The essence of citizenship is to be found in these enumerated rights as well as all those unspecified rights which flow to all citizens through our Constitutional heritage. A full life can be measured by the sum of the experiences and choices made throughout each individual's lifetime.

In this vision, and within a Constitutional and legal context, people, including people with developmental disabilities, will be treated and judged on a case by case basis. No conclusive presumptions, either in law or practice, will be made based merely on an

individual's disability, race, sex, creed, or ethnic origin. The governments of the United States and its states and territories will pledge themselves to promote respect for and observance of basic human rights and fundamental freedoms for all people, including those with developmental disabilities.

Procedural due process safeguards are mandated by the Fifth and Fourteenth Amendments of the United States Constitution. The essential elements of due process required are the right to be notified about actions that may deprive the individual of fundamental rights, an opportunity to be heard and to tell his/her side of the story, and the right that no conclusive presumption of fact or end result be permitted.

All people, including those with developmental disabilities, need to be informed about the nature and specifics of their rights under the Constitution and laws of the land. As for all citizens who seek to secure and protect their constitutional rights and statutory entitlements, advocacy must be available and affordable.

The vision of civil rights must also nurture the healthy development of children. Society must ensure that children will be raised with families among a community of friends and receive the education necessary for them to grow into independent and productive adults. They should be included in all aspects of life and the community and be allowed and encouraged to make choices. They must be allowed the chance to succeed or fail. All children should have the full benefit of the enjoyment of childhood with support from society and the government when necessary, protected from abuse, neglect and exploitation. Although the guiding legal and social principle in our society prefers parents to make the choices in circumstances involving life decisions for all children, including those with developmental disabilities, the concept of "best interests of the child" must remain the overriding principle so that children have the right to an advocate when necessary to protect their best interests. Society, and government as its representative, must be vigilant and ready to assist children when their best interests are not realized.

All of these rights contribute to and lay the groundwork for each individual's independence, productivity and integration into the community of citizens, the key to the exercise of the highest level of personal autonomy and responsibility possible. People with developmental disabilities, in common with all citizens, have an inherent right to live in dignity and to be treated with respect and equality before the law.

Persons with developmental disabilities share many of the same life problems with citizens without disabilities. Financial problems, abuse, civil rights denial, marital problems, lack of privacy, to name a few, are encountered by all citizens. People with developmental disabilities may encounter much greater difficulty, however, in resolving these problems when combined with barriers to access to legal representation and self-protection. Different types of decisions require different degrees and kinds of ability. The opportunity to make decisions for oneself is at the very core of a person's autonomy and yet such opportunities can be very limited for people with developmental disabilities, particularly for those who are institutionalized or who have mental disabilities. In the area of fundamental civil rights and citizenship, however, the severity of the disability should play a less significant role. No matter how severe the disability, all civil rights must be afforded to all.

People with developmental disabilities require assistance if they are to be included in this vision of full citizenship and rights. People with developmental disabilities need to be made aware of the supports and services that are available to retain a private attorney or legal advocate through publicly supported agencies. Other supports needed will depend on the type of disability a person has. People with mental disabilities may need more education, perhaps specialized, or need another person to assist them to make decisions. Those with physical disabilities may require accommodations to the environment such as communication devices, barrier free public facilities or personal attendant services to fully exercise their rights. Ensuring access to an attorney, for instance, may require assistance in transportation, communication, or in signing or reading a document. Other types of supports may include: accessible polling places, voter

education for people living in the community and in institutions, assistance in communication and mobility, and consumer education.

CRITICAL ISSUES

* Throughout history, people with developmental disabilities have been denied basic human and legal rights and been discriminated against for an other reason than that they have a disability. The discrimination experienced by people with developmental disabilities has been one of the most lasting barriers to their integration into the community and acceptance by society. Despite the fact that federal and state statutes and regulations have provided incremental gains, they have been insufficient to counter discrimination against people with disabilities.

Fifty-six percent of those surveyed by Harris whose onset of disability ranged from birth to adolescence believe that persons with disabilities are members of a "disadvantaged minority group" rather than disabled. (Harris Poll)

In the area of employment discrimination, 25% of working age people with disabilities believe that they have encountered job discrimination because of their disability. (Taylor, et al.)

Sixty-one percent polled by the Harris survey reported that job accommodations were not made. Thirty-five percent of those now working or with a history of full-time employment say that their employers made accommodations for their disability. (It is unclear from the Harris Poll and its analysis what type of accommodations were made or whether the accommodation was voluntary or the result of threatened or enforced legal action.) Forty-seven percent of people with disabilities aged 16-64 cite employer misconception about their disabilities as a major barrier to employment. (Taylor, et al.)

The federal government has attempted to prohibit discrimination based on handicap through various federal statutes. Prominent among them is the Rehabilitation Act of 1973, as amended, (P.L. 93-113). Section 504 was the first civil rights legislation to guarantee an equal opportunity for people with disabilities. It prohibits such

discrimination in programs and activities conducted by the federal government or by recipients of federal funds. Section 501 of the Rehabilitation Act of 1973 mandates affirmative action plans in employment practice for people with handicaps. Section 502 established the Architectural and Transportation Barriers Compliance Board which oversees efforts to make accessible public building and transportation systems. Section 503 prohibits discrimination in employment under federal contracts. The 1978 Amendments to the Rehabilitation Act made the antidiscrimination provisions analogous to the language in the 1964 Civil Rights Act and added Section 505 which provides attorneys' fees.

In 1983, the Montana Supreme Court held that a veteran or handicapped person who was qualified for a position within a state or local governmental agency had to be hired for the position even though there were other better qualified applicants (*Crabtree vs. Montana State Library*, 1983). This decision, based on laws passed in the 1920's caused quite a controversy and disrupted hiring by many governmental agencies.

In response to this controversy, the Montana Legislature met in December, 1983, and passed a new Veteran's and Handicapped Persons' Employment Preference Act. Although this Act repealed the absolute preference granted under the Crabtree decision, it does retain a governmental employment preference for Montana's handicapped. Under this new Act, a handicapped person who is substantially equally qualified for a position must be hired over a person not eligible for the preference. There are certain limitations for this preference (Montana Advocacy Program, 1985).

* A 2/3 majority of Americans with disabilities think that federal laws passed since the late 1960s intended to provide better opportunities to Americans with disabilities have proved beneficial in breaking down the barriers that keep them from independence, productivity and integration (Taylor, et al.).

* There is a lack of enforcement of the federal equal opportunity laws such as Section 504 by the Department of Justice, especially at the local level, which is a major barrier

to independence, productivity and integration into the community for people with developmental disabilities (Decker, 1989).

* Each federal agency is responsible for enforcing Section 504 for the programs it administers and funds. Primary guidance for interpretation of Section 504 implementation is found in the regulations each agency promulgated and the U.S. Department of Justice (DOJ) regulations establishing Section 504 standards for all agencies in drafting their own Section 504 regulations. Besides specifically defining such statutory terms as "qualified handicapped person," specific standards of conduct are set which are used to determine if conduct may be considered discriminatory.

* Each federal agency is also responsible for ferreting out disability related discrimination for its own in-house activities. Agencies are currently required to conduct a nationwide self-evaluation of their practices to ensure compliance with the nondiscrimination provisions of the Rehabilitation Act. In the self evaluation every agency is required to involve persons with disabilities. Some of the agencies are in the process of completing their evaluations now. The Department of Health and Human Services is required to have its draft published in the Federal Register by September 1989.

* Section 504 sets out the process that determines if unlawful discrimination has occurred, but misperceptions about people with developmental disabilities erode the effectiveness of the law. The courts are now revisiting Section 504 issues and the extent to which a renewed judicial inquiry may be necessary (Decker, 1989).

* Through the years, judicial decisions by the lower federal courts and the Supreme Court have undercut the effectiveness of Section 504. In 1984, the United States Supreme Court ruled in Grove City College v. Bell that Section 504 antidiscrimination requirements only covered the specific program or activity receiving federal funds, thus narrowing protections from those originally envisioned. Efforts were mounted to reaffirm the protective scope of the Section 504 by Congress and the disability and civil rights and women's rights fields. The Civil Rights Restoration Act of 1987 was passed to ensure that the entire institution was included under the antidiscrimination provisions.

* Other court decisions have led disability advocates to question effectiveness of Section 504 and its role in breaking down the last barriers in society for persons with disabilities. (Decker, 1989; See also, Perry J., Rights and Entitlements in the Community, 1985).

* Despite the enactment of Section 504 of the Rehabilitation Act, discrimination has yet to be tackled in the private sector or at the state level.

* The Fair Housing Act Amendments (FHAA) (P.L. 100-430) were enacted in late 1988 and became effective in March 1989 to mitigate against the limited scope of Section 504 protection in securing housing accommodations for persons with disabilities. The FHAA extends the antidiscrimination protection of Title VII of the Civil rights Act (The Fair Housing Act) to people with disabilities. Where Section 504 could protect persons with disabilities from discrimination in housing financed with federal dollars, the FHAA reaches private housing and rental accommodations. The FHAA provides the necessary vision and enforcement powers that will begin to tear down barriers in the community. Its reach into the private sector and its acknowledgement that people with disabilities belong in the community may be the most important tool thus far to educating society about people with disabilities. The Department of Housing and Urban Development is now empowered to fight discrimination in the sale or rental of housing, where as previous provisions only allowed informal conciliation by HUD. This law should fill the gaps in civil rights protection in those states with no or weak fair housing statutes or enforcement. The FHAA also requires local or state fair housing laws or ordinances to be "certified" by the Secretary of HUD as "substantially equivalent" to the FHAA. Certification requires that the local housing agency be substantially equivalent to the requirements of the FHAA in: protecting rights, procedures and remedies available for the agency to pursue on behalf of a complainant and submitting to judicial review of the agency's actions. All of these requirements may touch upon state or local laws which will need to be examined and evaluated for compliance.

* The Fair Housing Act is not being accepted everywhere and the states will have to play a vital role in seeing that its promise is fulfilled. In many states and localities,

legislatures will have to enact various statutes such as new zoning laws or new appellate procedures in state courts. (Councils can play an active role in the development of the newly required substantially equivalent laws.) In addition, the current practices and past history of state and local agencies will be examined as a prerequisite to their certification as substantially equivalent and capable of handling complaints arising from the new Fair Housing laws. The Secretary of Housing and Urban Development will refer complaints filed at the federal agency to local and state fair housing agencies only if they have been "certified." Ensuring that only those local agencies with the capability and desire to implement the FHAA are certified will play a vital role in the Act's effectiveness and vision for persons with developmental disabilities.

* Many people with developmental disabilities are unaware of existence of the Fair Housing Act and what its potential can mean to them personally in gaining desirable housing in the community and enabling them to make choices and achieve independence and integration.

* The limited scope of the Section 504 protections has lead the disability community to develop a more comprehensive approach to nondiscrimination which has been introduced in the house (HR) and Senate (S) as The Americans with Disabilities Act of 1989 (ADA). The ADA is an omnibus civil rights statute that reaches the private sector in its prohibitions against discrimination on the basis of disability. The ADA is an attempt to provide a clear and comprehensive national mandate to end discrimination against persons with disabilities, provide enforceable antidiscrimination standards and place the federal government in a central enforcement role. The ADA specifically prohibits discrimination against individuals with disabilities in private sector employment, all public services, public accommodations, transportation, and telecommunications. The general prohibitions were designed to be comparable to Section 504. Attorneys' fees are authorized for prevailing plaintiffs. If the ADA is passed and enacted into law there will still be a struggle to ensure its enforcement. The private sector may mount court

challenges to its constitutionality and statutory definitions. The ADA, however, holds promise as a true leveler for all citizens.

* Rights and protections need to be brought into balance. While some people with developmental disabilities may not become self-sufficient due to the nature and severity of their disability and may need protection and/or assistance in some life areas, others will reach independence. One of the most critical barriers to achieving autonomy and control over one's life is society's general misunderstanding of the ability of people with developmental disabilities and erroneous assumption that they lack the capacity for responsible decision-making. Presumptions are too often made in law and practice that if an individual needs assistance in one area of decision-making, such as financial planning, that individual must also require assistance in making other types of decisions, such as where to live or how to vote. Often, protection of the individual with a disability has been used as the rationale for many of the laws denying individuals their full rights. While society has a proper role to play in protecting its vulnerable citizens, the critical issue is how to do so without stripping away the essence of that person's humanity or overly restricting individual autonomy. One of the most critical barriers to civil rights is the denial of basic due process based on a person's disability. Substantive due process may be broadly defined as the Constitutional guarantee that no person shall be arbitrarily deprived of his life, liberty or property. Yet, many state laws affecting people with disabilities paint with a broad brush and label all people with disabilities far too similarly. People with developmental disabilities are denied due process rights on a regular basis when state laws assign certain characteristics to individuals because they have a disability.

Also, there are informal ways of denying rights to individuals with developmental disabilities. Families may create an atmosphere where the person with a disability is treated in a child-like manner and not encouraged to decide for him/herself what life activities should be pursued. This can be as great a barrier to independence as any state or federally sanctioned activity. The deinstitutionalization movement and the commitment to creating a welcoming community for people with developmental disabilities necessitates

efforts to ensure people can exercise personal choice, particularly, people living in institutions must be so empowered. Parents seeking to protect their sons or daughters must avoid denying their adult offspring the fundamental right to choose their place of residence. While for so many citizens with developmental disabilities choosing their own destiny and making decisions in almost every area of life can become a life struggle, research indicates that there are others who are indeed making life choices for themselves.

Fifty-three percent of all Americans with disabilities favor government and society action to enable them to attain self-sufficiency. Twenty-five percent of American with disabilities espouse that people with disabilities should be protected by society (Harris Poll). Between these two views are 22% of Americans with disabilities who register "unsure." This uncertainty as to the appropriate government approach may reflect a growing realization that persons with developmental disabilities must be considered as individuals and their needs assessed on an individual basis.

According to the Consumer Survey, people with developmental disabilities were able to make independent choices in various aspects of their lifestyle. As shown in Figure 29, Appendix F, in Montana 4% of people with developmental disabilities chose their present living arrangement independently, while 37% indicated choosing their living arrangement with assistance; 36% exercised control over their own money; 52% chose their friends and 31% determined their own social activities.

The appointment of a guardian can be the most intrusive form of state government intervention for a person with a disability, potentially reducing the capable adult with a disability to the status of a child. Guardianship is often granted when it is neither an appropriate nor adequate means to provide the assistance needed for people with developmental disabilities to achieve their fullest potential.

Guardianship statutes are matters reserved to the states. The federal government can intercede where there is a denial of federal Constitutional guarantees by a state law. Many state laws make presumptions about people with developmental disabilities and in

so doing can deny them fundamental rights under the Constitution. Decision-making rights are generally denied by a court determination of legal incompetence or incapacity. When a court makes a determination of legal incompetence or limited capacity of someone with developmental disabilities, it is usually followed by the appointment of a guardian. The court may give the guardian only limited decision-making authority or, as is more common, very broad powers over the person such as financial and personal care decision-making authority. Such decisions can affect the ability of the person with developmental disabilities in areas such as the right to marry, the right to decide whether to have or refrain from having children, sexual freedom and sterilization rights, licensing, voting, contracts, adoption rights, right to refuse medical treatment, civil commitment procedures, criminal procedures, and the right to testify in court (Brackel, 1979).

A National Guardianship Rights Act, (HR 1702, S 235) has been introduced in the U.S. Congress and although the bills target senior citizens, their coverage extend to people with developmental disabilities. The legislation includes federal minimum standards for potential guardians, enumerates the substantive and due process rights of persons alleged to be incompetent, and provides for the presence of attorneys as advocates. While not legally binding on the states, since guardianship laws are essentially state matters, federal financial and other incentives and disincentives are provided for states adopting or not adopting the federal guidelines. (Copies of the National Guardianship Rights Act, H.R. 1702, may be obtained through the Subcommittee on Health and Long Term Care, Select Committee on Aging, H2-377, House Office Bldg. Annex II, Washington, D.C. 20515: (202) 226-3381).

Model guardianship standards, fundamental principles and definitions are included in the House Subcommittee on Health and Long Term Care, Select Committee on Aging, Report, "Proposed Model Standards for Programs Providing Guardianships and Representative Payeeship Services to Adults."

A model statute on guardianship and standards for adjudication of competency were prepared by the American Bar Association's Commission on Mental Disability in 1979 (Brackel, 1979).

Because there is a lack of support and assistance available in the community to enable people with disabilities to make choices most citizens take for granted as more people move into the community, resources will be needed to sustain their independence. As this happens, there is a fear that states will tend to appoint more guardians rather than provide needed support services to promote independence and true integration in the community.

* Major barriers to civil rights enforcement for people with developmental disabilities are the lack of advocates and attorneys who can help to secure their civil rights. Access to attorneys or advocates for persons in institutions has been a major barrier to the protection of civil rights for persons with developmental disabilities. The issue faced by most Protection and Advocacy agencies is insufficiency of their resources. The Consumer Survey reports that 31% of citizens with developmental disabilities in Montana indicate a need for legal or protective services.

The Developmental Disabilities Assistance and Bill of Rights Act (P.L. 100-146) requires states to establish Protection and Advocacy systems (P&As) to protect the rights of persons with developmental disabilities. P&As handle cases that run the gamut of problems for persons with developmental disabilities: education, discrimination, abuse, wills, commitment to institutions, employment, housing, habilitation, finance, day care, contracts, and constitutional and architectural barriers issues.

The 1988, Protection and Advocacy agencies for persons with developmental disabilities across the country handled 58,312 cases. (NAPAS 1988)

The Montana Protection and Advocacy Agency, Montana Advocacy Program, Inc., authorized by the Developmental Disabilities Assistance and Bill of Rights Act, was established in 1977. In 1988, MAP formally opened and pursued 160 cases involving

persons with disabilities. Numerous others were provided assistance through outreach and other forms of activities.

* Protection and Advocacy agencies have had difficulty in gaining access to recourse in institutions as well as to the clients. Notice is required, sometimes as much as 24 hours in advance, before an attorney can visit his/her client in an institution. Such limitations, usually set by the institution, create barriers to effective advocacy and can act as barriers to uncovering abuse and neglect in institutions. Where it is difficult to gain access to a client, it becomes even harder to gain access to potential clients. While federal statutes provide for access to attorneys in general, they do not always adequately address the issue of the reality of access (Decker, 1989).

The Civil Rights of Institutionalized Persons Act (CRIPA) passed in 1980 empowers the Department of Justice to initiate action to protect the constitutional and federal rights of people in institutions, among them persons with developmental disabilities. (P.L. 96-247)

* Because CRIPA encourages settlement out of court in many cases as possible, there has been an apparent lack of resolve on the part of the Department of Justice to take the necessary legal action to make the protections available under CRIPA come to life. (cite pending)

* Under the Civil Rights for Institutionalized Persons Act (CRIPA), it is unclear whether Protection and Advocacy agencies have a right to initiate actions. It was generally assumed that the Department of Justice had enforcement authority; but, in the face of serious inaction on the part of DOJ, P&As are eager to pick up the mantle and intervene.

* Although voting is a fundamental responsibility of American citizens, many people with physical and mental developmental disabilities do not vote, due to barriers to their participation. Increasing activity in this aspect of community life will increase interaction between voters with disabilities and voters without disabilities and can help to dispel the

perception of persons with disabilities as powerless, replacing it with a healthy regard for the value and power of all citizens.

* Although much progress has been made, many polling places are still not accessible by objective standards (Federal Election Commission, 1989). The issue of voting rights for state and local elections has not been addressed in any federal legislation.

Voter turnout in the United States in the last federal election was only 48.7% of the electorate (League of Women Voters, 1988). In Montana's Consumer Survey, the percentage of people with developmental disabilities voting in the most recent election was 13.2%.

For the 1988 general election, 79% of the 145,969 polling places surveyed were determined to be accessible. This figure represents an improvement of six percentage points (approximately 6,000 polling places) since 1986 despite more stringent criteria (Federal Election Commission, 1989).

* Forty states prohibit certain classes of people with mental disabilities from voting. Montana's voting laws do preserve the right to vote for persons with developmental disabilities (Brackel, 1987).

* Many state laws have negative consequences for the person with developmental disabilities affecting voting rights and the exercise of other rights such as commitment to institutions, adjudication of competency, or appointment of guardians (Brackel, 1987). (Model statutory language for voting competency tests was developed by the American Bar Association's Commission on Mental Disability.)

The Voting Rights Act of 1965 provides the right to choose a voter assistant in the exercise of franchise rights. The assistant may accompany the person with a disability into the booth or other polling place and physically vote for the voter. This assistance enables the voter with a disability to participate in the fundamental right and responsibility of citizenship.

The Voter Accessibility for the Elderly and Handicapped Act (P.L. 98-435) encourages citizen participation while also promoting integration into the community by

enabling persons with disabilities to access polling places. The U.S. Attorney General is authorized to bring action for violations by state and local election officials. Although a private right of action is authorized, no attorneys' fees are provided unless it is an action to enforce a previous judgment.

- * The effectiveness of the statute, however, is somewhat diminished by its weak enforcement provisions. For example, states may set their own standards for determining accessibility with no requirement that there be an accounting for the standards. The states are also responsible for self reporting their compliance.

- * People with developmental disabilities are not always aware of their rights and avenues for legal redress and there is a lack of outreach and education in the area of civil rights, particularly the ability to informing people with disabilities that they have a right to enforce their rights and seek redress against those very individuals and agencies providing the education and advice. At times, a proper understanding of civil rights will place people with developmental disabilities at odds with their advocates, families and/or guardians, who then have a conflict of interest.

- * Seventy-nine percent of Americans with disabilities report not being familiar with Section 504 antidiscrimination provisions. (Harris Poll)

- * There is a lack of outreach to underserved minority groups and limitations to making full use of recent advocacy legislation for persons with disabilities (Decker, 1989).

- * In many areas of legal representation, conflicts of interest arise regarding the issue of attorney loyalty. This is a particularly problematic area when the client with developmental disabilities has cognitive limitations or communication difficulties. Attorneys must be clear that it is the person with the disability, and not a third party who may be paying the attorneys' fees, who is being represented.

- * There is a great lack of in data available in the area of civil rights for people with developmental disabilities.

NADDC RECOMMENDATIONS

1. The Americans with Disabilities Act should be enacted during the 101st Congress as the main vehicle to secure and enforce nondiscrimination in the private sector and in state government activities.
2. States should adopt State Bills of rights or Equal Rights Amendments for Persons with Disabilities to state constitutions. States can ensure that their state laws include strong nondiscrimination provisions and enforcement provisions.
3. Surveys of state laws should be done in each state to identify those laws that impede the independence, productivity, and integration of persons with developmental disabilities.
4. Guardianship as a means of assistance should be considered as a last resort for persons in need of decision-making guidance and then only limited in length and scope as necessary for independent living. There should be uniform national standards to protect persons under guardianship from abuse or denial of civil legal rights which provide incentives for other forms of assistance in decision-making such as individual and family support and advocacy in both the community and in institutions and less restrictive protective interventions such as increased case management for persons in the community. Standards should state that in any adjudication of competency or capacity which may result in the appointment of a guardian, no matter how limited, the proposed ward should be given sufficient notice prior to the hearing and be present and represented by counsel of the his or her choice. The National Guardianship Act of 1989 should be enacted and states should adopt its guidelines in the conduct of guardianship proceedings and in the determination of a person's competency.
5. The American Bar Association should review the Professional Code of Responsibility concerning such representation and develop guidelines for attorneys in the disability field to eliminate issues of conflict of interest, such that their interests are guided solely by the interests of their client. Also, encouragement

must be offered through recruitment efforts to those attorneys and local bar associations to join the disability rights movement.

6. CRIPA's enforcement authority needs to be expanded so that P&As may initiate suites on their own.
7. Governments at all levels should discard the presumption that there is a relationship between a developmental disability and the decision-making capacity to vote. When a state chooses to erect a competency test to determine eligibility to vote, this test should apply to all voters and not just those with developmental disabilities. Further, a policy of affirmative action should be developed and implemented for people with developmental disabilities living in institutions regarding voter registration and voting. It should be the policy and practice of state and local governments that assistance will be available and accessible on a nonpartisan basis for those requiring it to exercise voting rights. Voter registration should be made as easy as possible for all potential voters.
8. Beyond access to services and supports, exercising civil rights requires receiving those supports. Access to a waiting list does not advance the vision of full citizenship for people with developmental disabilities. Thus, expanding entitlements to individual and family supports services, such as through the Medicaid Reform efforts under consideration in the 101st Congress, must be accomplished.

MONTANA RECOMMENDATIONS

The primary source for Montana's recommendations is the Temple University Consumer Survey conducted by our state in 1989. Recommendations derived from the survey are followed by parenthetical reference to specific item numbers in the survey, indicating the percent of respondents dissatisfied with a particular service and the total number of respondents to that particular item. If the issue also arose during the public forums, that source is noted in the parenthetical reference as well.

1. Protective or legal services individualized to meet the unique needs of persons with disabilities need to be reinforced (Item 6.5: 40% of 10; forums).
2. The concept of companions and friends within advocacy programs needs to be explored and enhanced to better provide assistance for persons with disabilities (Item 6.17: 41% of 17).
3. Availability of and information about guardianship services should be more readily accessible and comprehensible (forums).
4. Consent by persons with disabilities for medical procedures, behavior programs, financial decisions and sexual activity should be studied and addressed in a more systematic, comprehensive and clearly delineated manner (forums).

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